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HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN

HEARING

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

NINETY-NINTH CONGRESS

FIRST SESSION

ON

EXAMINING THE NEEDS FOR PEDIATRIC HOME CARE FOR CHILDREN WITH LONG-TERM ILLNESSES AND DISABILITIES

JUNE 18, 1985

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HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN

TUESDAY, JUNE 18, 1985

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The committee met, pursuant to notice, at 9:20 a.m., in room SD-430, Dirksen Senate Office Building, Senator Orrin Hatch (chairman of the committee) presiding.

Present: Senators Hatch, Kennedy, Thurmond, Metzenbaum, Dodd, Nickles, Pell, Hawkins, and Grassley.

OPENING STATEMENT OF SENATOR HATCH

The CHAIRMAN. If we could, we would call the committee to attention. We will call the Labor and Human Resources Committee to attention. Before we begin, we would appreciate it very much if people will not smoke during this hearing. We have young children on oxygen in this room and so we are going to ask our police to make sure that nobody smokes while we are in this room.

We are happy to have you all here today, and we are certainly happy to have our guests and our witnesses here today. Today, we are holding a full Labor and Human Resources Committee hearing devoted to home health for chronically ill children.

Imagine with me, if you will, a little girl born prematurely weighing only 2 pounds, 3 ounces, but with no other significant medical problems. She is allowed to leave the hospital after 2 months, but is readmitted with viral encephalitis some 4 months later.

During the next 3 years, she fights the devastating after effects of this debilitating respiratory disease. Unfortunately, when her doctors prepare to release her from the hospital, her family discovers that Medicaid will not cover the cost of her home health care.

Does it seem to you that this child would be better off confined to a hospital without her family and friends, or would this child be better off at home with the same quality care being provided by the family she loves at a savings of about $30,000 per year to the taxpayers, or at least to whomever? I think the answer is obvious.

In an effort to restrain public health expenditures, too often the Federal Government has been short-sighted, failing to recognize the obvious cost savings which could result if we strengthened reimbursement policies for home care.

For children who are dependent on respirators for breathing, home care could save as much as $30,000 per year per patient. For

children with even more complicated problems, there are estimates of even greater cost savings. For example, for a child requiring intensive care in a hospital, the costs may be $250,000 per year from a team care standpoint.

Team care in the home setting for the same youngster might cost approximately $60,000 per year, or only 20 percent of the hospital cost. Results like these have not been routinely attainable because of obstacles encountered under standard reimbursement policies. However, times are changing.

One of the first examples of the more enlightened approach occurred in 1981 when President Reagan helped to clear a Medicaid waiver for Katie Beckett, followed by the President's personal endorsement of home health care.

Katie is here with us today and we will hear more about the way this Medicaid waiver has made it possible for Katie and her family to be together, sharing their day-to-day life, along with the very special joy of Katie's care. The now famous Katie Beckett waiver was a step in the right direction, but more needs to be done, and that is what this hearing is all about.

I am a committed advocate for improved home and community-based care—a system that does make it possible for citizens to obtain the help they need to stay in the comfort and the security of their own homes.

I recently introduced the home health care block grant of 1985, S. 1181, to assist the elderly in achieving this goal. Today, though, we will not limit ourselves to this legislation, but focus on what is happening to a smaller, very critical segment of our population—our children.

Infants and children who suffer from serious, chronic medical problems that require sophisticated medical care are all too often trapped within institutions. They are trapped not because the care they need cannot be provided at home, but because reimbursement through public and private insurance makes it impossible for them to obtain the services they need at home.

I am aware of the arguments, pro and con, regarding the cost of home care. I have had many occasions to listen to individuals concerned with this issue, both advocates and opponents. And this hearing gives us an opportunity to learn about what has worked, what holds promise for the future, and what we might do in Congress to improve the lot of some of our most precious citizens.

I am amazed at the courage and cheerfulness of most of the youngsters I have met. They put up with what seems like an unbearable burden; yet, they greet each day with enthusiasm. This courage can be fostered and maintained when they are in the nurturing, nourishing environment of their own homes.

Now, I am pleased to welcome our witnesses with us today, the children and their families with their informed perspective—Katie Beckett and her mother, Mrs. Julie Beckett, who can tell us what has happened since they got the ball rolling, with the help of President Reagan; and representatives of the administration. These folks are going to inform us of current reimbursement policies and research related to home health care for children, and we look forward to having them all here today, along with Susan Sullivan, whom we very happily welcome to the committee.

We will turn to Senator Metzenbaum at this time.

Senator METZENBAUM. Mr. Chairman, first I want to commend you on holding this hearing and indicating your concern. It is quite obvious that what you were saying met with the approval of the children because I could hear several of them out there cheering you on while you were speaking. [Laughter.]

I know of no hearing or no subject that concerns me more than this one, and I am hopeful that we can work together legislatively to solve some of the problems that face these families that meet such an overwhelming challenge.

The testimony we will be hearing today, I am confident, will be a moving reminder of the needs of our chronically ill or handicapped children, and I trust that it will move us to prompt action in overcoming the barriers to the kind of health care that would best meet those needs.

The Beckett family is to be congratulated for having pioneered in overcoming one of those barriers, and I am particularly pleased to see them here this morning. I am looking forward to hearing their testimony on the Katie Beckett Medicaid waiver, which certainly appears to be a model for sensible and cost-effective adaptation and use of health care resources.

Their experience—and it oftentimes takes the experience of a living example of an individual—dramatizes the need to combine bureaucratic regulations with sensitivity and common sense, which we all know is in no way common.

Most often, the patient prefers home care, and understandably so, and so does the family. Common sense, experience, and even research tells us that institutionalization is not the most effective solution for children requiring long-term health care, just as it is not the most effective solution for any chronically ill or handicapped person, whatever the age.

I have not hesitated to speak out and indicate my concern about those senior citizens afflicted with Alzheimers. The health problems of the children and the health problems of our aged are serious and diverse.

It has been estimated that 1 to 2.8 million children have handicap conditions sufficiently severe to limit their daily activities significantly. These are brave children, and their parents are even more brave. We appreciate their courage in being here to help us understand the difficult handicaps they must battle. It is a battle against odds so great that our help is absolutely essential.

The prophet Isaiah spoke of peace when he said, "and a little child shall lead them." Today, we speak of health, and I believe the children here today shall lead us to better understanding and to action based on that better understanding.

I want to say that I am grateful to the chairman for having set up the hearing and for leading us on this subject. I am particularly grateful to the parents who are with us here today and their children because they provide a living example, a very dramatic example of why we in the Congress have an obligation to act. We will not let you down.

The CHAIRMAN. Thank you, Senator Metzenbaum.

We will turn to Senator Thurmond at this time.

Senator THURMOND. Thank you, Mr. Chairman.

Mr. Chairman, it is a pleasure to receive testimony this morning on an issue in which I have a very special interest. As the father of four healthy young children, I am constantly reminded of how blessed Nancy and I have been, and we are eternally thankful. When any of our children get sick or become injured in their recreational activities, there is nothing more important than to ensure their health needs are met.

We are lucky that their health problems are relatively minor in nature and occur infrequently. Many children do not share this good fortune. Today, nearly 4 percent of the children in our country are chronically ill. The lives of their parents revolve around the special health needs these children constantly require. No greater love can be shown than the courage these parents and children demonstrate in their daily ability to deal with such major health problems.

The children that are here today are beautiful. They have life and they have a future. Advancements in medical technology have enabled them to live at home with their parents. The quality of their lives has been improved because they do not have to live in a hospital.

Millions of dollars in medical expenses have been incurred in the few years these children have been alive. Most of these expenses are in-patient hospitalization charges. Home health care is much less expensive than in-patient care.

Unfortunately, most health insurance programs which are readily available focus their coverage on hospitalization. These parents are more fortunate than others with chronically ill children. At least they have been able to obtain medical insurance coverage which allows their children to live at home.

I would like to thank the lovely Ms. Sullivan, the parents, the children, the medical providers and the Government Administrators who have given unselfishly of their lives to come here today and increase public awareness on this very important issue.

I hope that this hearing will make elected officials, insurance providers, and health care providers throughout the country more aware of this problem. Hopefully, a solution can be achieved which would reduce health care costs and provide for the special needs of chronically ill children in a home environment.

Because of my responsibilities as the chairman of the Judiciary Committee, scheduling conflicts prohibit my attendance for the full hearing today. However, I look forward to reviewing the testimony presented by these fine witnesses.

Thank you, Mr. Chairman.

The CHAIRMAN. Well, thank you, Mr. Chairman.

Senator Kennedy.

Senator KENNEDY. Thank you very much, Mr. Chairman, and I too want to express my appreciation to you for holding these hearings this morning. I would like to submit my statement in the record as if read.

The CHAIRMAN. Without objection.

Senator KENNEDY. I want to just make a very brief comment. I first of all want to express my appreciation to the parents joining with us here today and their children. I think it is extremely difficult for parents to talk about the illnesses of their children. For

some reason, I think all of us like to keep those kinds of matters personal, and it is understandable.

But I think it is important for them to know how important their experience is to us here in the Senate, talking about matters which not only affect their children, but which are replicated all over this country.

There is a crying need for leadership. I think it is common sense that when it is medically appropriate, a child ought to remain home. There are circumstances where that is not possible, but in the broad range of homes in this country, that is something which clearly is in the child's interest, and if it is medically suitable, that is where the child ought to be, getting the support and the care and the love and the affection of the family and all of the kinds of support that can be provided for that child.

I am sure, as we are going to hear this morning, it can be done at a lot less cost, a lot less cost, in terms of the families and in terms of whatever the systems are that are providing financial aid and assistance.

We know that those kinds of inhibitions in keeping children in institutions are the direct result of a wide variety of programs—Federal programs, State, and private insurance. And we can here in the Senate make a significant difference in terms of the Federal programs, particularly in the Medicaid Program and other Federal programs—the CHAMPUS programs, the Federal health insurance programs.

We in the Senate can make requirements that States are required in their eligibility programs for Federal funding that they are going to provide this kind of service for children to remain at home. And by this kind of leadership, we can lead, hopefully, the States and we can lead the private sector in this extremely important area of public policy.

I start these hearings with that as a hope and as an objective, and look forward to working with our colleagues to see if we cannot achieve that. I want to thank all of you once again for joining with us.

[The prepared statement of Senator Kennedy follows:]

PREPARED STATEMENT OF SENATOR EDWARD M. KENNEDY

I am pleased to be here today for our hearing on home care for chronically ill children. This is a vitally important topic and one that deserves real commitment from our Nation's policymakers. I have worked closely with Senator Hatch on the development of these hearings and I am delighted he has made this topic a priority for our committee.

The record is clear that it is often a human and financial disaster to institutionalize children when home care is safe, effective, and clearly desired by the children and their families. Both public and private reimbursement policies, however, have too often dictated that home care will be denied even in cases where the same care would be covered in a hospital or other institution.

That policy is sometimes justified on the grounds that health care dollars should be reserved only for those who truly need that care. Services in the home, it is argued, are usually for less acutely ill persons, and the availability of public or private insurance would displace current contributions families make out of their own resources.

I am skeptical of the validity of that justification in any context, but whatever its general validity, it is clearly not applicable to the population of children needing intensive medical services that we are discussing today. Indeed, these seriously ill children have far too often been victimized by that policy.

Although these children need critical and complex medical therapies, it is now possible to provide that care in the home. Home is where children belong, and a policy that keeps children in their homes should be the priority of our Committee and all public policymakers.

There are children here today who would have spent their entire lives in hospitals or skilled nursing facilities except for the courageous and unceasing advocacy of their parents and health professionals caring for them. These children have won a reprieve. We must act to assure the same care for all chronically ill children.

Without assistance, there is no family that can afford the care or provide the supervision and case management necessary to sustain children at home with these complex conditions. Federal policy to assure the availability of the services our families and children need is imperative.

There are children here today who have saved literally hundreds of thousands of dollars of public money by returning to the loving home environments that only their families can supply. In order to provide that loving care, families have been forced by backward, antiquated public and private policies to make unnecessary sacrifices.

The families here today have pledged their energies, and their full time commitment to care for their children at home. This has sometimes necessitated job changes, moving from one state to another, and enlisting the help of neighbors, community resources, and relatives to ensure an environment where their child can live and prosper.

The burdens of having a severely ill child are difficult enough without the obstacles posed by backward, antiquated, public and private health policies. No family should have to move in order to get appropriate insurance coverage. No family should have to undergo lengthy struggles with public and private bureaucracies to get the care their child need. And, most of all, no family should be forced to relinquish the care of their child to a medical institution when that child could be cared for at home.

We need to move quickly to assure that the progress made by the individuals here today can be made available to all children in institutions who could, with appropriate services and insurance coverage, be at home with their families.

Policy formulated from the testimony of the expert witnesses and heroic families here today can save public dollars, can protect and sustain invaluable family resources, and can bring children home.

The future work of our committee must be focused on a program that will develop and make available a coordinated program of community based services for severely ill children. I look forward to the dialogue during this hearing which will guide us in developing the best possible home care service for severely ill children.

The CHAIRMAN. Well, thank you, Senator Kennedy.

We are pleased to welcome this morning four panels of witnesses who will provide us with their views and experiences regarding pediatric home health care. Our first witness will be Ms. Susan Sullivan, a highly accomplished actress who has pleased millions of Americans every week, and I think people all over the world, as Maggie Giaberti in the popular series "Falcon Crest."

I might add that Elaine and I are very upset at your husband right now. [Laughter.]

Ms. Sullivan is also a respected advocate for home health care, and so we are really pleased to have you here. We appreciate you taking time out of what we know is a very busy schedule to come and share your views with us, so we are grateful.

We will also hear, after Ms. Sullivan, from Ms. Karen Buckholtz, Ms. Angela Bachschmidt, and Ms. Patty Cook, whose children are all currently receiving home care. We want to thank all of you for coming. It means a great deal to us and a great deal to what we are trying to do.

We are pleased to take your testimony at this time, Ms. Sullivan. Again, thanks for coming.

STATEMENT OF SUSAN SULLIVAN, MEMBER, BOARD OF TRUSTEES, FOUNDATION FOR HOSPICE AND HOME CARE; KAREN BUCKHOLTZ, PASADENA, MD; ANGELA AND MICHAEL BACHSCHMIDT, WASHINGTON, DC; AND KEVIN AND PATTY COOK, BOSTON, MA

Ms. SULLIVAN. Thank you. I am afraid I am going to be a little redundant. It seems that you gentlemen have sort of summed up what I am going to say. As an actor, that makes me nervous; I hate to sort of repeat myself.

But for the record, my name is Susan Sullivan. I am here today as a member of the board of trustees and as spokesperson for the Hospice Organization. I became involved with hospice when my father died of cancer. He died at home.

My family, and indeed my father when told that he was going to be going home—our initial response was fear. It just seemed like a new idea to us. If you were sick, then you should be in the hospital. And I cannot tell you how much it meant for my father and for us as a family to have him home and to spend those last months of his life together in a way that we never could have simply experienced in a hospital.

Now, these children that you see before you—they are wonderful, by the way; I have spent a little time with them—have been hospitalized most of their lives. They were born and raised in rooms virtually without windows. Their playmates have been other sick children and nurses and doctors.

Today, these children, led by the very brave little Katie Beckett and her extraordinary mother—and all of these parents are to take your breath away; they are so wonderful. These children are now being cared for at home in a way that most children simply take for granted. And yet there are millions more who are not being given this simple advantage.

Ten million chronically ill children in this country—somewhere between 1 and 2 million of them are as severely impaired as the children you see before you today. They have conditions most of us have heard about, but few of us understand—spina bifida, sickle-cell anemia, cystic fibrosis, muscular dystrophy, hemophilia, leukemia, chronic kidney disease, severe asthma, birth defects. It is not easy.

What these 10 million children have in common is chronic illness, which may or may not be life-threatening, but which is almost always lifelong. Unlike most childhood diseases which are brief and predictable, these conditions and the costs for caring for them extend over a long period of time.

Now, what they also have in common is technology. Modern technology has kept them alive; the same technology made their lives possible. Now, largely because of technology, many infants now survive who simply would not have a few short years ago.

Largely because of this technology, the number of chronically ill children in our society has doubled in the last 25 years, from about 2 percent to about 4 percent. The children you see before you, though chronically ill and severely handicapped, have a future. They have something most of us can recognize and identify with as a reasonably normal life, and I can attest to that.

Brandon—hi, Brandon. That is Brandon down there, the little guy with the great smile who has one of my earrings. [Laughter.]

Ms. SULLIVAN. That is all right, Brandon.

Brandon ran up a hospital bill of half a million dollars before he came home. His total health bill probably approaches $1 million over the 3 years of his life. He was a premature baby. He was injured as the doctors labored to save his life and, as a result, he needs some assistance breathing. But he is getting better. You should see him climb up and down those stairs; he is extraordinary. And there is reason to believe he will outgrow his dependence.

Now, Robert—Robert is this little guy back here—has surprised everybody, with the exception of his parents, I assure you, by talking when he came home. You know, I think this is really one of the most important things. These children do so much better at home; they really flourish.

He has a rare muscle disease. He needs some help sitting. He cannot feed himself or breathe without the help of a ventilator, but he kissed me; I swear to God.

Erin, sitting behind me--where is Erin? She is all the way back there, OK. She has generated more than $2 million in medical bills in her 5½ years of life, and yet with monitoring, she goes to school, she takes ballet lessons, and leads a nearly normal life.

These are truly the million-dollar babies. They are fortunate to be alive; they are doubly blessed to have parents who understand the importance of family and are willing to sacrifice to keep it whole.

David—David is here somewhere; he is Brandon's dad—had to change jobs in order to get the kind of medical coverage his son needed. Karen, his mother, has delayed returning to nursing school to be by his side.

Robert's family has endured relocation three times in order to find a State where their son could receive the care he needs. Now, that is three moves, three different States, three different jobs, three different schools for the other two children.

Erin's parents have gone through three insurance companies to provide the services that she needs. Through it all, her mother persevered and somehow found the strength to seek out others in similar circumstances and help bring them home.

Now, for each of these children, there are hundreds of others not so fortunate. Hundreds, maybe thousands, of children now hospitalized could be cared for at home if a determined effort were made.

Here is the big surprise: The biggest obstacle, as any of these parents can tell you, is funding. Our existing system is a patchwork of programs and it is very easy for something as fragile as a child to fall through the cracks.

Insurance programs are limited and are focused on hospitalization. Chronic illness requiring home care is treated as an exception to policy. The programs respond to need for home care only on demand. Federal and State programs are similarly limited.

Benefits and eligibility vary from State to State. At the moment, for example, there are two children in Children's Hospital in Washington who could be cared for at home and indeed who would be cared for at home if they lived in the other two States, not Maryland, which refuses to cover them for nursing care. If Mary-

land covered them, their nursing care would be reduced by two-thirds.

You know, some people have suggested that the technology that makes many of these lives possible has gotten out of hand, and they raise a very difficult ethical and philosophical problem and I think they miss the point.

The point is that the technology is here and, more importantly, the children are here. And given that fundamental fact, our obligation is to see to the quality of their lives and to let them lives as normal an existence as possible, and that simply cannot happen in a hospital, and it is not necessary.

The same technology that makes their lives viable and has been perfected to the point where they can be cared for at home and can, in fact, be right here in this room with us makes the difference. So, you see, the policy has not kept up with the technology.

What these children need is a systematic program that recognizes their needs—a system that is flexible enough to adapt to the uniqueness of each situation and provide the assistance necessary.

The fact that the necessary care can be delivered at home at a fraction of the cost is a welcome dividend, allowing us to extend the care needed to greater numbers without increasing the cost, and I hope that was not too technical.

I thank you very much, Mr. Chairman, for allowing me to be here and to speak, and I want to thank the committee for their continued interest in the chronically ill child. You know, in this very extraordinary country of ours, with such a wealth of land and such a wealth of industry and such a great generosity of spirit, where people are raising billions of dollars to feed the starving children of the world, certainly we are not going to turn our back on the millions of chronically ill children in our midst.

Together, we can give them a more meaningful life. All it takes is a recognition of the magnitude of the problem and then the will to do something about it, and I know you have that. I mean, just look at your faces.

Thank you very much.

[The prepared statement of Ms. Sullivan follows:]

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OPENING STATEMENT

OF

SUSAN SULLIVAN

BEFORE

THE UNITED STATES SENATE

COMMITTEE ON LABOR AND HUMAN RESOURCES

JUNE 18, 1985

Mr. Chairman, members of the Committee:

My name is Susan Sullivan.

I am here today as a member of the Board of Trustees and spokesperson for the Foundation for Hospice and Homecare.

I have been involved with hospice since the death of my father. He died at home of cancer. My family's first response to the suggestion he come home was fear. It was a new idea. If you were sick you were supposed to be in a hospital.

But I can't tell you how much it meant for him and for us to have him home. We lived the last part of his life together as a family, and that is something we never could have shared in a hospital.

Most of the children who appear before you today have been hospitalized most of their lives. Most of them were born into and raised in a world without windows. Most of them can remember when their only playmates were other sick children, doctors and nurses.

Led by a brave girl named Katie Beckett, and her extraordinary family, some of these children have found the nurturing and warmth most children take for granted. But there are still millions more who don't have this simple opportunity.

There are 10 million chronically ill children in the country. Somewhere between 1 and 2 million of them are as severely impaired as those you see before you today.

They have conditions most of us have heard about but few of us understand. Spina bifida. Sickle cell anemia. Cystic fibrosis. Muscular dystrophy. Hemophilia. Leukemia. Chronic kidney disease. Severe asthma. Birth defects and the like.

What these 10 million children have in common is chronic illness, which may or may not be life-threatening, but which is almost always life-long. Unlike most childhood diseases, which are brief and predictable, these conditions and the cost of caring for them continue over extended periods of time.

What they have in common is technology. Modern technology has made many of their lives possible. The same technology keeps many of them alive.

Largely because of technology, many infants now survive who would not have a few short years ago. Largely because of technology, the number of chronically ill children in our society has doubled in the last 25 years - from about 2% to about 4% of all children.

The children you see before you, though chronically ill and severely handicapped, are the children of fortune. They have life. They have a future. They have something most of us can recognize and identify with as a reasonably normal life for a child.

Brandon, sitting beside me with the beautiful smile, ran up a hospital bill of half a million dollars before he came home. His total health bill probably approaches a million over the three years of his life.

He was a premature baby. He was injured as the doctors labored to save his life. As a result, he needs some assistance breathing. But he is getting better, and there is reason to believe he will outgrow his dependence.

Robert, on my other side, has surprised everybody but his family by beginning to talk since he came home. He has a rare muscle disease. He needs help sitting. He can't feed himself or breathe without the help of a ventilator.

Erin, sitting behind me, has generated more than $2 million in medical bills in her five and one-half years of life and yet, with monitoring, she goes to school, takes ballet lessons, and leads a nearly normal life.

These are the million dollar babies. They are fortunate to be alive. They are doubly blessed to have parents who understand the importance of family and are willing to sacrifice to keep it whole.

Brandon's father had to change jobs in order to get the kind of medical coverage his son needed. His mother has delayed returning to school to be by his side.

Robert's family has endured relocation three times in order to find a state where their son could receive the care he needs. That's three moves. Three different states. Three different jobs and neighborhoods. Three different schools for Robert's older sister.

Erin's parents have gone through three insurance companies to provide the services she needs. Through it all, her mother perservered and somehow found the strength to seek out others in similiar circumstances and help them bring their children home.

For each of these children, there are many others not so fortunate. Hundreds, if not thousands, of children now hospitalized could be cared for at home if a determined effort were made.

The biggest obstacle, as any of these parents can tell you, is funding. Our existing system is a patchwork of programs. It's very easy for something as small as a child to fall through the cracks.

Insurance programs are limited and are focused on hospitalization. Chronic illness requiring home care is treated as an exception to policy. The programs respond to the need for home care only on demand.

Federal and state programs are similarly limited. Benefits and eligibility vary from state to state. At the moment, for example, there are two children at Children's Hospital in Washington who could be cared for at home and would be cared for at home, if their families lived in either of the other two states the hospital serves. But Maryland, so far, has refused to pay for the nursing services these children need, even though the result would be to reduce their ongoing health costs by two-thirds.

Some have suggested that the technology that makes many of these lives possible has gotten out of hand. They raise profound ethical and philosophical questions.

But they miss the point The technology is here. More significantly, the children are here.

Given that fundamental fact, our obligation is to see to the quality of their lives and let them live as normal an existence as possible. That can't happen in a hospital.

And it isn't necessary. The same technology that makes their lives viable has been perfected to the point where they can be cared for at home; can, in fact, be here in this room.

What these children need is a systematic program that recognizes their needs, a system that is flexible enough to adapt to the uniqueness of each situation and provide the assistance necessary.

The fact that the necessary care can be delivered at home at a fraction of the cost is a welcome dividend, allowing us to extend the care needed to greater numbers without increasing costs.

Mr. Chairman, I am pleased to have had this opportunity to appear before you today. I applaud your interest and the

Committee's continued interest in the plight of chronically ill children.

Our country is blessed by the wealth of our land and the industry and generosity of our people. A nation that will raise billions of dollars to feed the starving children of the world will not turn its back on the millions of chronically ill children in our midst.

Together, we can make their lives more meaningful. All it takes is a recognition of the magnitude of the problem and the will to do something about it.

Thank you.

Ms. SULLIVAN. I would now like to pass—I was going to say pass the buck—I would now like to pass the microphone to Karen Buckholtz and her son, Brandon.

Karen?

Ms. BUCKHOLTZ. Good morning, Senator Hatch and other members of this distinguished committee. My name is Karen Buckholtz and I appreciate the opportunity to testify here this morning in behalf of pediatric home care.

My husband, David, and I live in Pasadena, MD. We are the parents of three children—our baby daughter, Shana, age 5 months, and our 3½ year-old twins, Brenda and Brandon. Brandon is the reason I am here today.

When Brandon and his sister were born in October 1981, they were 3 months premature. We were told they had a 25 to 50 percent chance of surviving. As you can see today, my children beat those odds. However, their condition was so fragile initially that I was terrified.

The first thing we asked was can we hold them, but the doctor said no. It was 6 weeks before we were ever able to hold them. I will never forget the first time I saw them. There were a lot of machines, tubes. The nurses had warned me that there would be a lot of these things, but I said, sure, sure. I was still expecting these chubby little babies maybe with a mask over their face, but it was not like that.

There were wires everywhere and the babies were bruised and they were so tiny. I cried. I had to turn around, Although I was warned, nothing can prepare you when you see your own babies lying there like that.

After about 4 months, we were able to bring Brenda home, with some chronic lung damage, but Brandon was not ready. He would have frequent respiratory arrest and he had to be resuscitated constantly. He would pull his tubes out and they would have to keep putting them back in, and the frequent trauma caused damage to his airways.

Because of the damage, they felt that Brandon would have to have a temporary tracheostomy. Originally, they thought there was just a lot of swelling from the trauma. They were going to put him on some special medication and in about 6 weeks they thought they would be able to take the trach tube out. That was over 2½ years ago.

The doctors said there was a lot of weakness in his trachea and that it should heal, but each time that we go back, they say Brandon is not ready. We are still hoping that as long as we can maintain his airway and keep him going, eventually he will reach a point where he will outgrow this.

Modern medical technology kept Brandon alive, but medical and other support services, as well as funding mechanisms, have not kept pace with the technology. The result has been an unbelievable series of obstacles and setbacks to us in our efforts to get Brandon out of the hospital environment and into our home and family life.

Once Brandon stabilized, we knew we wanted to bring him home, but we also wanted to bring him home safely. We wanted to feel that we were not going to doze off in the middle of the night, sleep

through his alarm, and find that he passed away in the middle of the night.

We wanted to know that there was somebody able and ready to respond when need be, and we could not do it alone. We wanted to know that he was going to get proper medical care. We wanted to know that he was going to get physical therapy. We wanted to know that we were properly prepared and that we were qualified to handle an emergency when we were alone and had to do it.

We wanted to make sure we had all the equipment and all the supplies that Brandon needed, but David and I did not know if we were prepared. Getting all the information and the all the help we needed was a nightmare.

First of all, you have got to have a pediatrician who understands home care. If the pediatrician cannot understand that the needs of the family have to be considered, then it just will not work. That is what happened to us at the beginning.

Our first pediatrician decided somewhere along the line, because of all the obstacles we encountered in getting home health care, that we could take care of Brandon alone because we had been trained to do it. This meant that either one or both of us would go without sleep. That just did not work.

The thing that was so strange was that this particular pediatrician was the exception and not the rule. All the other people we had met who had respirator-dependent or respiratory failure children had pediatricians who were 100 percent behind the family. They asked the families what they needed to keep their child at home, and then they wrote the proper letters to obtain it.

Our pediatrician would not do that, so we got a different pediatrician, Dr. Samuel Williams. Dr. Williams is excellent. Without him, Brandon would be in an institution today, because you have to work together to get these kids home. It is almost like a marriage—David and me and Dr. Williams.

We also had so many problems getting the funds to pay for Brandon's care at home. The financial burdens have been extraordinary. David was working for the Federal Government and although he had high-option Blue Cross and Blue Shield, no one wanted to actually interpret what that coverage entailed.

For example, we had a 90-day home health care provision which allowed for in-home health care for 90 days following a covered admission. But no one wanted to say how much nursing care was actually available under that provision. There was a reference elsewhere in the policy to nursing care for 2 hours per visit for 50 visits.

There were some people who said that what was in that provision on nursing care applied to the home health care section as well. We could not do anything with that kind of coverage. David actually had to change jobs in order to get the insurance coverage that would help us to keep Brandon at home.

There were other problems along the way, too. When we first brought Brandon home, we did not have a reliable nursing agency. They sent a nurse without properly screening and briefing her. She did not know she was dealing with a trach baby and she was not qualified to handle him.

She caused him to go into rapid fire respiratory arrests and Brandon had to be medivaced back to Johns Hopkins Hospital. So we were facing obstacles from all sides. We could not find proper nursing care for Brandon, and in any case our original insurance company was refusing to pay for it.

In desperation, I went through the telephone book calling every agency that looked like they might be able to help. I just hoped I could find someone who could give us the funding that we needed.

Finally, we went to the media to try to get some support, but there is a real problem out there with lack of any kind of coordinated support. We have got to get the powers that be together to decide that it is better to have a child at home; that it is more cost-effective to have the child at home than it is to keep the child in the hospital.

There is a need for agencies that can help, that can tell parents where to go to get equipment. They can help by setting up interviews with nursing agencies so that the parents can find a nursing service that can meet their child's specific needs.

There is a need for resources for parents to find out where they can take their child for developmental assessment and intervention, if need be. There is a need for a service to direct parents to good pediatricians who are oriented toward home care.

I think the existing reimbursement mechanisms, public and private, also need to be better oriented toward the concept of home care. Our child belonged at home and a lot of others who are currently in institutions belong at home. Our experience showed that it was much more cost effective to care for Brandon at home.

Yet, insurance companies that will pay thousands and thousands of dollars for care in a hospital will not pay a fraction of that amount for nursing and other support services in the home. It just does not make good sense, and I am sure you do not think so either. But that is the way a lot of payors operate, and parents have a hard time dealing with these unnecessary barriers that are put up along the way.

At bottom, there is a lot of information that parents need to face in situations like these. You do not know you are going to have a child like this until the child is here, and then it is like you are stuck in the middle of the ocean and do not know how to swim. There needs to be somebody out there with a life preserver to kind of give us a hand.

Because of all of the problems we faced, David and I have often been asked why we ever made the decision to bring Brandon home. I think the No. 1 reason is because he is our son, and a second reason is that nowhere else could Brandon have half the chance that he has being at home.

Institutions try hard, but they cannot care for a child the way the parents can. Now that Brandon is home, he has people he can learn to trust after being in the hospital for a year. He really did not have that there. He did not know that when he was hurting, somebody was going to come or that when he was hungry, somebody was going to feed him.

Brandon and the other children like him were being cared for and loved on a schedule. They did not get the kind of love and affection that they can get at home. While Brandon was in the hospi-

tal, he did not develop the way he should have emotionally or mentally. We wanted Brandon to have the best possible chance at leading the most normal life possible under the circumstances, and the only way we could give him that chance was to bring him home.

Now that he is at home, Brandon has made great improvements along the way, although he is still somewhat delayed. But when we think about what he would have been like if he had to stay in the hospital, there is just no way we can really make any kind of comparison because there is no comparison. Home is where he should be because that is the best place for him.

Thank you again for giving me the opportunity to be here this morning. David and I and other parents like us appreciate the attention your committee is giving to these very important problems and we will do everything we can to help you find solutions.

Thank you.

The CHAIRMAN. Well, thank you, Ms. Buckholtz.

Ms. SULLIVAN. Thank you, Karen. Now, we are going to hear from Angie and Mike Bachschmidt—the mother of Robert.

Mr. BACHSCHMIDT. And father.

Ms. SULLIVAN. Yes.

The CHAIRMAN. If we could move that mike over so Ms. Bachschmidt can be heard a little bit better, if you will put it right over next to her mouth.

Ms. BACHSCHMIDT. Pardon?

The CHAIRMAN. If you can get that one mike, the silver mike, over with you—put them all close to you. The silver mike is the one that will amplify you in this room; the others are for the television cameras.

Ms. BACHSCHMIDT. Dear honorable committee members, we are Michael and Angela Bachschmidt. Our son, Robert, who is 2½ years old, has spent the majority of his life in three hospital intensive care units. The more recent stay has been at Children's Hospital National Medical Center in Washington, DC.

Robert suffers from a rare, severe form of muscular dystrophy. In August of 1983, our son was admitted to the intensive care unit of Portsmouth Naval Regional Medical Center in Portsmouth, VA. Our son was suffering from severe pneumonia and needed to be placed on a ventilator to save his life.

After several weeks at this hospital, it became apparent that in order to better care for Robert's acute needs, he needed to be transferred to Children's Hospital of the King's Daughters in Norfolk, VA. After 8 months at this hospital, it was obvious that due to his muscle disease, our son would need the assistance of a ventilator probably for the remainder of his life.

In October 1983, we approached the staff of Children's Hospital of the King's Daughters on the feasibility of intensive care at home for our son. Considering at this point Robert had already been stabilized, there was nothing we wanted more than to have our son at home.

The staff at King's Daughters informed us at this time that neither their hospital nor the State of Virginia had the necessary resources to properly care for Robert's acute needs on a long-term basis. They also did not have experience or staffing available for intensive home care.

At that time, Robert's pediatric intensivist started inquiring of hospitals on the east coast that would have home care programs already established. We waited for a response from each hospital whether or not they would accept us. We were turned away from Philadelphia Children's Hospital and Bethesda Naval Hospital. Our only hope was Children's Hospital National Medical Center here in Washington, DC.

In November 1983, we were scheduled for an indepth interview with the home care staff. After the interview, we had to wait for the decision to be made whether or not we would be accepted. In April 1984, 6 months later, Children's Hospital had an opening and we were then accepted.

My husband, Michael Bachschmidt, is a first-class engineman, E-6, in the U.S. Navy. The Navy graciously granted us a humanitarian transfer to Washington, DC. At the time of our transfer, CHAMPUS had agreed to endorse Robert's home care and to pay for his medical needs.

After transferring to the Washington area, we learned that they would only cover a small percentage of Robert's home care costs. CHAMPUS will pay a maximum of $1,000 a month. This amount would not even cover the rental cost of Robert's equipment, much less needed supplies and nursing care. He remained at Children's Hospital another 9 months, a total of 18 months of hospitalization in all.

The medical staff there would not discharge Robert without skilled nursing. Their $1,000 maximum would not allow for this. Due to Robert's muscle disease, his life expectancy is believed to be shortened. Our greatest wish has always been to have him home with us, his family, where he could receive the love he needs. Our son's life should be one of quality.

CHAMPUS will pay for Robert to stay in the intensive care unit, but will not provide adequate funds for home care. This makes no sense, especially considering home care has many advantages, including cost effectiveness.

Current documentation indicates the cost of home care is approximately one-third of the cost of hospital intensive care for acute, chronically ill, technology-dependent children such as Robert. In each case, there have been substantial cost savings to the State Medicaid programs, private insurance companies, and individual taxpayers.

The following is an approximation of Robert's costs. His hospital cost per day is $1,200; per year, it is $558,000, plus physician's costs of $18,000, which makes a total of $577,200 a year.

For home care costs, his nursing care for a year will cost $54,496. That is 16 hours per day. His supplies cost $12,000 and his doctors, $1,000, which makes a total of $67,496.

The advantages of home care for the chronically ill child are well documented. One often sees the child's medical status improve. Often, there is a decrease in the number of infections the child experiences. The child is more likely to approach or attain appropriate social development and emotional health.

Home care professionals such as social workers, nurses, and therapists provide positive family support—a much-needed resource. The benefits are having a happy home with some stability

to it and as normal a lifestyle as can be achieved with a child that has special needs.

During the 18 months of our son's hospitalization, we were trained every day. We went every day to see him unless we were ill. We had technical and assessment skills we had to do over and over again until the hospital felt we had mastered the all-around skills that they would have expected of a qualified technician.

Although we were Robert's parents, we were still treated as though we were qualified technicians and had to perform under the expectations as such. Once Robert was released from the hospital, he would be totally dependent upon our medical judgment.

These are areas that took a lot of training and a total of 1,500 hours. That is approximately 2 hours a day, but often we spent very long hours at the hospital that exceeded the 2-hour average.

We had a reason for wanting to learn Robert's care and a reason to sacrifice time which we needed to spend with our other two children. We knew that the end result of our labor would produce a better quality of life not only for Robert, but for our whole family.

Every child that has a life-threatening handicap is different in many ways. No one child is alike. Therefore, no single law or cap can take care of every child's needs. Please help each child's specific need in maintaining him or her at home the way you would treat each illness with different drugs and treatment. You cannot treat cancer the way you would treat pneumonia. The needs may be different, but they all have one thing in common. They need to be home.

Thank you very much.

The CHAIRMAN. Thank you, Ms. Bachschmidt, and you also, Mr. Bachschmidt.

Mr. BACHSCHMIDT. Yes, sir. The children that are behind me and the one beside me are very special. They are beautiful; they have certain special needs. They are not handicapped in my book; they just have special requirements.

I have been all around the world and I have seen that this is the best Nation; we have the best country. The United States of America is special to me. I cannot see us restricting home care. I cannot see us not allowing our children to be at home and receiving the family care that they deserve and they need.

Also, there was a question brought up as far as sacrifice. What is a family without sacrifice? Our family, we have sacrificed, but it has paid off. Look at our son behind us. They expected him to live a month when he first went in the hospital; then it was a couple of months. Then it was, well, he will not live throughout the year.

He has not slowed down. He is 3 foot 6 inches tall and weighs 43 pounds, and I love him. And I think every one of these children deserves to be home.

Thank you.

The CHAIRMAN. Well, thank you.

Ms. SULLIVAN. Oh, Mike, thank you.

Now, we are going to hear from Kevin and Patty Cook, who are the parents of Lauren. Kevin?

The CHAIRMAN. Of course, we are happy to welcome you here as well.

Mr. COOK. Thank you. Good morning. My name is Kevin Cook, and this is Patti and Lauren. Lauren is our second child. She is 5 years old. She spent the first 5 years of her life in Boston Children's Hospital.

When Lauren was born, it was suggested to us that we move to Boston.

The CHAIRMAN. Could you move your mike just a little bit closer, Mr. Cook? That is good.

Mr. COOK. Lauren was born in Pittsburgh. The doctors there suggested to us that we move to Boston, which we did. When we moved up there, we were fortunate in having some family closeby in New Hampshire, so we moved to New Hampshire because someone at the Social Security office told us that it really did not matter in which State we lived. Lauren was going to be a recipient as long as she was a resident of Boston Children's Hospital; the Medicaid would be provided.

Six months after that, we were told that they made a mistake and that we had to leave our home in New Hampshire and move about 7 miles across the border into Massachusetts, where we still are. It would be nice to get back closer to our family, if possible.

Our presence here today was made possible in part by New England Critical Care, our TPN supplier, and the Federation for Children With Special Needs. Lauren is constantly infused by this pump here. She has a mal-absorption problem; it is the condition that she has.

And we have built this pump into this cart to get us mobile. In the hospital, this pump was connected to a large pole which restricted her from going outside of the hospital. Our daughter, Lauren, is a high-tech child, a child whose life literally depends upon the machines to which she is attached.

A decade ago, Lauren would probably not have lived past her first birthday. I do not know that I mentioned we had a child; our first son was born with the same condition and he died in Pittsburgh Children's Hospital at 7 months old.

Advances in the medical community have made it possible for her and many other children to survive in spite of their illnesses. Hospitals throughout the country have within them many children suffering a variety of disabling diseases that could possibly be managed at home, but because of regulations governing payment of medical expenses based upon the family's financial qualifications, these children must remain in the hospital.

Not only would medical expenses be decreased significantly, but the quality of life of these children and that of their families would greatly improve. Every child deserves a chance to grow up at home with their families in a loving, nurturing environment, and technical advances of modern medicine have given them that chance.

Now it is up to the legislators of such regulations to update their policies to deal directly with the barriers that are keeping these families apart. The Katie Beckett waiver is one step in the right direction. The benefits of this waiver have already begun to be realized in our case.

Lauren's medical bills averaged $320,000 per year at Boston Children's Hospital. It is estimated that her home care will eventually cost about a third of that. Part of that cost is our nursing staff.

Lauren's care is extremely demanding and our nurses give us a much appreciated respite from this stressful situation.

At present, Medicaid provides our nursing care through an agency, but as of June 21, 1985, this arrangement will be subjected to Medicaid's review and reapproval. It could be determined that we no longer require the agency's services and that our nurses could then apply for Medicaid vendor numbers and be reimbursed by Medicaid directly.

This in itself is not a problem, but the nurses would then be asked to wait 3 months for their names to be processed through the computer and receive their first paycheck. This unreasonable request could cost us all of our nursing staff.

For the first 90 days, the agency provides an invaluable service by interviewing, hiring, and coordinating the nursing staff, thus lifting a very heavy burden from the parents. This is probably the most stressful time in the child's home care planning.

Perhaps during this 90-day period, the nurses could be processed so as to eliminate the possibility of losing them later.

Our biggest challenge was redesigning and finding someone to build a new cart to house Lauren's new TPN equipment. Medicaid agreed to pay for a new cart because it would eventually save them from $55,000 to $65,000 per year in decreased supply costs.

At first, we hoped that New England Critical Care would be able to direct us to a medical company that would be interested in creating this new piece of adaptive equipment, but neither anyone that they approached nor any of the professional people we contacted were willing to help.

When time became a factor, we contacted another agency, Lifeline, and they arranged for a local voc tech school to build a cart if we would provide them with the technical drawings needed. This is what we eventually did.

This whole ordeal was very frustrating. Parents burdened with providing their special needs child with the best possible equipment would benefit greatly from some type of central resource center.

Finally, and most important to us, is what would happen to Lauren if Patti and I were to meet with some accident and perhaps die. Ideally, we would appoint either my sister or her husband or Lauren's grandparents as guardians, but we are not certain that this is possible due to the fact that she is a Massachusetts Medicaid recipient under the Katie Beckett waiver and our families reside out of State.

The major problem is the disparity of benefits that each State attaches to its SSI Program. Would any insurance money or trust funds established for Lauren alter her Medicaid waiver status?

If my sister, who lives in New Hampshire, were to become her guardian, would they then be held responsible for Lauren's medical expenses? Our worse fear yet: Would she be made a ward of the State and be reinstitutionalized in order to continue her present quality of medical care? Or less?

What is needed here is a definite policy dealing with this issue that would provide equalization of benefits across State lines; also, clarification of guardianship responsibilities related to medical expenses.

We have worked very hard to create a home environment that would provide her with the moral and spiritual foundations needed to allow her to become a mature and responsible adult. We feel it is imperative that she be permitted to continue to grow within this same environment which our families have also established.

A new policy dealing with this issue would allow parents in this same situation to feel more secure about their children's future.

Thank you for inviting us here. We hope that we have been of some help.

[The prepared statement of Mr. Cook follows:]

PREPARED STATEMENT OF MR. AND MRS. COOK

December 7, 1984

Dear Sirs:

We have been asked to try and summarize Lauren's medical history and explain why we feel it is so important to have her at home with us. This is not an easy task because Lauren's needs are so complex, but we will try.

She has been at Boston Children's Hospital since birth due to a rare intestinal condition which causes her to suffer a secretory diarrhea and severe mal-absorbtion. She is completely unable to support herself by oral nutrition and has been sustained totally by total parenteral nutrition (TPN). This requires the surgical insertion of a catheter into larger interior veins in either the neck, legs or chest. So far Lauren has had approximately 8 life lines and each subsequent line becomes more difficult to obtain. Now, each new life line requires a thorocatomy and a recovery period in the medical intensive care unit. Because her very life depends upon these lines, we treat them with the utmost care. Her blood is monitored regularly for any early signs of infection.

She has done very well these last two years and as you can see from her picture, looks extremely healthy. The staff, especially the nurses on Division 27, have worked very hard to help her have as normal a childhood as possible under such abnormal circumstances. The result is a happy, outgoing, loving, intelligent and somewhat mischievous 4½ year old.

But we have now reached a point where Lauren's needs have surpassed what help Boston Children's Hospital is able to offer. There are three basic areas in which we feel Lauren would benefit greatly by being allowed to live at home. These areas are her medical, emotional and spiritual welfare.

There is a saying at the hospital that goes, "a hospital is the worse place for anyone to be, just because practically everything a person could catch is there." Because Division 27 is a medical floor, children are admitted with a myriad of viral and bacterial infections. Lauren, therefore, runs the risk of exposure to more than just the usual childhood diseases. Caring for her at home would greatly reduce this exposure.

At present, Lauren appears to be a well adjusted child with the normal 4½ year old tendencies -- stubborness and independence. The doctors assure us that these are healthy signs because most institutionalized children tend to be subdued and may withdrawl into themselves. We have worked very hard to avoid this syndrome and instead strive to make her feel loved and secure. We are with her six days a week and when we can't be there, we call her and talk with her over the telephone. The nursing staff has been a tremendous support to all of us.

But, as Lauren grows older, we are faced with emotional problems that become even more complicated by her continuing hospitalization. The principle reasons we feel Lauren needs to be home are as follows:

I. She is over stimulated.

She is over stimulated by all the people and activities that surround her and she has a very difficult time entertaining herself. She prefers walking the halls and watching the elevators to reading a book, coloring or playing with her toys. she is much too vicarious in that she relies heavily upon others to, more or less, play for her. A subdued surrounding would compel her to discover and develope her own interests and talents.

II. She is under stimulated.

In another sense she is extremely under stimulated. Day after day it's the same place, same people and same routine. Because she

has had such limited exposure to the outside world, she has little or no knowledge of it. Just last month she was thrilled to discover the moon and the stars. She is an extremely inquisitive child, and we fear that if that curiousity is not continually nurtured and fed, it will surely die. A new home life and school life would make a world of difference.

In addition her life is filled with needles, blood tests and operations. Every day there is at least one painful experience. A life in such an environment simply can not be healthy for anyone let alone a child. She needs to be home -- to be given the opportunity to enjoy pleasurable things and at least have some painless days.

III. Her changing school needs.

Lauren is fast becoming school age. She does attend a speech and hearing pre-school program two days a week that is offered at the hopsital which has helped develope her attention span a great deal. The problem is, though, the program is really geared to small toddlers, ages 2-4, with speech & hearing impediments. Lauren has been attending for one and a half semisters and is no longer a small toddler nor does she have any real speech & hearing problems. Her primary needs are more in the social areas. It is imperative that she learn to play and associate with children her own age or older, so as not to become an introvert, but instead to give her a sense of self-confidence and to teach her how to relate to other people. On February 24, 1985 she may no longer qualify for this program and the best alternative the hospital can offer is a tutor which would not meet her primary needs at all.

IV. Her growing sense of desertion by friends and family.

Even at an early age Lauren was rather outgoing and she would endear herself quickly to other youngsters on Division 27. Usually the children would be like herself in that they were hospitalized for lengthy periods and also had a life line. They would become like family to each other because of their common circumstances. Over the years she has suffered the loss of these friends due to their recovery or their death. She has also lost many nurses with whom she had become very close when they left to start families or take other jobs. This was particularly hard when they were her primary nurses. They were her "mother substitutes" in my absence. Unfortunately, this is an all too recurring problem. Recently, we ahve noticed that when she does meet a new friend, she becomes very possesive. The poor child is then unable to even go to the bathroom without Lauren breaking into tears for fear he won't return. And also, we are now having an increasingly difficult time leaving her at night. She begs us to stay "just a few more minutes." It just seems that being left behind is a way of life, and we wonder what effect this will have on her ability to relate to people in the future.

V. She lacks a true sense of home and family life and her own role within the family unit.

I am with Lauren six days a week, but my husband's visits are restricted by his job. He can only see her Tuesday, Thursday and Sunday, so therefore, although we try to be with her as much as possible, our time together as a real family totals only about 11 hours a week. This is simply not enough time for any of us.

Plus, her extended family is more abstract than reality since she has never even met some of them and others are just a voice on the telephone. Hopefully, a home life and continuous personal relationships with her nearby cousins will create a feeling of stability and permanence that she so desperately needs but can never obtain at the hospital.

In September, I had a special carriage built that houses her TPN equipment which because she can push around by herself, has added a whole new dimension to her life. She can only use the carriage for eight hours a day, but for the first time in almost two years she is independent of the IV pole that has held her captive for so long. Since then, she has enjoyed being home on about six occasions. At times, these arduous and brief trips home seem more like a cruel tease, except for the fact that now the word home has a more tangible meaning. She constantly chatters away about her own room and all the things we will do when she goes home and really stays there. We all pray that day comes soon.

VI. Her need for an environment that offers a more consistent discipline training.

Every small child spends a great deal of time and energy testing their parents authority and thereby developing their sense of right and wrong. Through these many trial and error experiments, they learn which actions are appropriate and which are not. They also realize which actions reap their parent's praise and which may harvest only undesirable consequences.

For most children this is a natural process only complicated by older brothers or sisters. But in Lauren's case, not only is she dealing with mom and dad, but at least twenty other authority figures (mainly nurses) with varying temperments. Therefore, the problem is that even though the staff has been very cooperative in attempting to create an atmosphere of consistency, there are times where her behavior is accepted by some people yet not tolerated by others. Plus their responses to her behavior are as wide ranging as their personalities, yielding confusion on Lauren's part. Lauren needs to come home to eliminate this confusion from her life.

Basically, we feel that all things considered, Lauren has done very well in her emotional development. But the conditions under which she has lived these last 4½ years have been so abnormal that we can't help but fear what effect her hospitalization will have upon her future. She deserves the opportunity to experience and to enjoy her home, some happiness and to be cared for by her loving and devoted parents. She needs the direction and security that only a home life can afford.

Finally, and most important, she needs the spiritual guidance, support and fellowship that only a church can offer. Our church's Sunday School programs would not only provide the moral and spiritual foundation upon which we as a family can build, but also friendships that will endure.

The Lord has become essential in our lives and the source of much strength, peace and direction, especially in times of trial. Lauren's life has been and probably will continue to be filled with difficulities. So we want to give her a chance to have a personal relationship with the Lord as well, so that she may receive that same peace and strength.

I hope that we have been able to help you in some way. We do appreciate the time and effort you will spend evaluating our situation. Thankyou.

Sincerely,

Kevin, Patti and Lauen Cook

The CHAIRMAN. Well, you surely have. I want to thank you, Mr. Cook.

Ms. Sullivan, I am impressed that somebody as busy as yourself would be willing to take time out to help chronically ill children and their families. We are very, very pleased to have you here. This testimony has been very poignant and very moving to me, and I know to other members of the committee. This has been a terrific hearing thus far.

Let me just ask you one question, Ms. Sullivan, and that is this: I understand that children who have chronic and severe illnesses need a broad range of medical services, but they also need emotional support. I think that is important to note, too.

What do you recommend might be done to give the families and the kids the psychological support that they may need?

Ms. SULLIVAN. Well, you know, the mothers here have formed a group called SPIKE?

Ms. BACHSCHMIDT. SKIP.

Ms. SULLIVAN. SKIP; I had all the letters. [Laughter.]

I think that is the kind of organization you need—people you can talk to who are having the same problem that you can reach out to. It is in that reaching out and extending of yourself that you find your own strength. These mothers and these families here are the leaders; they are the front runners. Does that answer the question?

The CHAIRMAN. Emotional interrelationship that the families themselves could have.

Ms. SULLIVAN. Yes.

The CHAIRMAN. Let me just ask one question to each of you parents, and give me the best answer you can, and that is this—I would really like to ask a number of questions to you, but I am going to limit myself to one so other Senators can ask, and also so that we can listen to the remaining witnesses here today.

From your experience, what is the single most kind of support that you really need? I mean, what would you like to see us expand in legislation in order to help you to keep your children at home and to care for them at home?

Why do we not start with you, Ms. Buckholtz? The single thing that you need the most to help your children and to keep them at home?

Ms. BUCKHOLTZ. Financial assistance.

The CHAIRMAN. OK.

Ms. BACHSCHMIDT. Funding.

The CHAIRMAN. Mr. Bachschmidt, do you agree?

Mr. BACHSCHMIDT. The same thing, funding.

The CHAIRMAN. OK. What about you folks?

Ms. COOK. I think that is right.

The CHAIRMAN. The same thing, so the single thing you need help with is financial assistance. Where we have waivers, that is some assistance, but where you do not have waivers, there is an awful lot of difficulty. It is apparent that we do need to bring our legislative enactments into the modern world, into the high-tech world, and to help these kids.

I want to tell you how beautiful each of your children really is. We are really proud to have you here.

Let me turn to Senator Kennedy.

Senator KENNEDY. Thank you for very moving and very compelling testimony. I want to welcome the Cook family to Massachusetts. We are proud of our State for many reasons, but certainly because it reaches out in perhaps a more understanding way in terms of some of these health needs. Hopefully, it is a reflection of the kind of concern of the people of that State in terms of health.

You know, it does not really surprise me, the response you gave to this question with regard to financial assistance, because it seems to me that the anguish which a family is faced with in terms of the complexities in which a child is trying to develop and to grow and to be able to reach its own potential—and the parents are trying to help that child through a difficult period of time—is enormously moving and has to be enormously draining.

It provides obviously, I would expect, an incredible sense of satisfaction, and combined with love and religious belief, it is a very compelling and moving experience. But to have that complicated by wondering whether you are going to be able to survive and what is going to happen to your child—we heard from the Cook family in terms of their own lives—and to be constantly worried whether in another few weeks some bureaucrat, well intentioned as he or she might be, is going to making some decision that is going to make a difference between life and death for your child, and to be faced with that kind of anxiety day in and day out must be a burden of just overwhelming proportions, overwhelming proportions.

And it seems to me that one of the challenges in terms of our own humanity as a society ought to be that this child is sick and how are we going to take care of that child in the best and the most effective way in terms of the family, in terms of the child's needs, and not whether you have to move around to a dozen different States to get coverage or have to change your job in order to get another kind of health insurance program.

That story has been told to this Congress for years. You have told it eloquently. You have reminded us again and, quite frankly, you ought to keep speaking of this issue until we are going to do something about it.

I just cannot tell you how impressed I am by this testimony. I think there is an ability for us to do something about it. I hope that we will take action, but I certainly join the members and the chairman of this committee in insisting that we are going to give the opportunity for the Members of this body to vote up and down in this Congress whether we are really serious about caring for these children and caring about their parents.

I find it so troublesome that half of all the testimony we hear is all about the kinds of restrictions and regulations and the door-knocking at this insurance company or that State. You know, you just have to ask yourself in terms of our society, do we care about children and what is our sense of decency and humanity.

This panel has reminded us about that this morning and I think it is a very good service.

Mr. Chairman, I have questions of this panel and the others that I would like to submit for the record.

[The following were received for the record:]

QUESTION FOR MRS. ANGELA BACHSCHMIDT

WHAT WAS THE HARDEST BARRIER TO OVERCOME FOR YOU IN YOUR EFFORTS TO BRING ROBERT HOME?

QUESTION FOR SUSAN SULLIVAN, ACTRESS

FROM YOUR PERSPECTIVE, MS. SULLIVAN, WHAT ACTION IS MOST NEEDED BY CONGRESS TO ENABLE MORE CHRONICALLY ILL CHILDREN TO BE CARED FOR AT HOME?

QUESTION FOR MRS. KAREN BUCKHOLTZ

WHAT HAS BEEN THE MOST DIFFICULT PROBLEM TO SOLVE IN BRINING BRANDON HOME?

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QUESTION FOR MS. BETSY DAVIS

IT HAS BEEN SUGGESTED THAT A BROAD BASED HOME CARE PROGRAM MIGHT BE OVERLY EXPENSIVE BECAUSE OF THE DIFFICULTY IN ASSURING THAT ONLY THOSE TRULY IN NEED BECOME ELIGIBLE. AS A NURSE ADMINISTRATOR OF AN AGENCY PROVIDING HOME CARE TO A LARGE PEDIATRIC POPULATION, HOW DIFFICULT DO YOU THINK IT WOULD BE TO PROVIDE A VALID SCREENING PROGRAM FOR ELIGIBILITY, SO THAT ONLY THOSE WHO WOULD OTHERWISE BE IN INSTITUTIONS WOULD RECEIVE SERVICES?

QUESTION FOR MR. KEVIN COOK

YOUR DAUGHTER HAS BEEN HOME FOR JUST THREE MONTHS. OUTSIDE OF THE WHOLE REIMBURSEMENT SYSTEM, CAN YOU TELL US WHAT POSES THE MOST PROBLEMS FOR YOU IN OBTAINING NEEDED SERVICES FOR LAUREN?

QUESTION FOR ARTHUR KOHRMAN, M.D.
DIRECTOR OF LaROBIDA CHILDREN'S HOSPITAL AND ASSOCIATE PROFESSOR
PEDIATRICS, UNIVERSITY OF CHICAGO SCHOOL OF MEDICINE

WE'VE HEARD TODAY ABOUT THE IMPORTANCE OF THE PEDIATRICIAN ON A HOME CARE TEAM. IN YOUR OPINION ARE HEALTH PROFESSIONALS GENERALLY KNOWLEDGEABLE ABOUT THE FULL RANGE OF COMMUNITY AND MEDICAL RESOURCES NEEDED FOR THOSE KINDS OF CASES, OR SHOULD THE CONGRESS CONSIDER FUNDING EXPANDED TRAINING FOR SERVICE DELIVERY AND CASE MANAGEMENT?

QUESTION FOR ARTHUR KOHRMAN, M.D.

WHAT HAS BEEN YOUR EXPERIENCE IN THE ADEQUACY OF REIMBURSEMENT AVAILABLE FOR FAMILIES OF HOSPITALIZED CHILDREN WHO WANT TO CARE FOR THEIR CHILDREN AT HOME?

QUESTION FOR WESLEY WALKER

1. IN YOUR OPINION, ARE THERE SUFFICIENT NUMBERS OF HEALTH PROFESSIONALS SKILLED IN PEDIATRIC HOME CARE TO MANAGE CARE FOR THE COMPLEX NEEDS OF THESE CHILDREN?

QUESTION FOR WESLEY WALKER

2. IN YOUR EXPERIENCE, WHAT IS THE BIGGEST BARRIER, OTHER THAN FINANCING, FOR FAMILIES IN THEIR ATTEMPTS TO BRING THEIR CHRONICALLY ILL CHILDREN HOME?

QUESTION FOR LIZ AHMANN, R.N.

1. MS. AHMANN, YOU HAVE BEEN PROVIDING HOME CARE TO CHRONICALLY ILL CHILDREN. IN YOUR OPINION, WHAT SERVICE DEVELOPMENT MOST NEEDS TO BE UNDERTAKEN IN COMMUNITIES?

QUESTION FOR LIZ AHMANN

2. CAN ALL FAMILIES SAFELY CARE FOR CHRONICALLY ILL CHILDREN AT HOME, OR ARE THERE BASIC REQUIREMENTS? FOR INSTANCE, CAN SINGLE PARENT FAMILIES ASSUME THIS BURDEN?

QUESTION FOR JULIANNE BECKETT

1. MRS. BECKETT, YOUR EFFORTS ON KATIE'S BEHALF HAVE BEEN EXTRAORDINARY, AND MANY PARENTS AND CHILDREN ARE BENEFITTING FROM THE WAIVERS FOR HOME CARE THAT WERE DEVELOPED THROUGH YOUR ADVOCACY. CAN YOU TELL US WHAT THE BIGGEST UNMET NEEDS STILL ARE IN PROVIDING HOME CARE FOR CHILDREN?

QUESTION FOR JULIANNE BECKETT

2. CONSIDERING THAT MANY STATES ARE UNWILLING TO APPLY FOR WAIVERS, DO YOU THINK IT WOULD BE REASONABLE FOR THERE TO BE A REQUIREMENT THAT ALL MEDICAID PLANS PROVIDE HOME CARE WHERE FEASIBLE FOR CHILDREN WHO WOULD OTHERWISE BE HOSPITALIZED? AND DO YOU THINK PRIVATE INSURANCE COMPANIES SHOULD BE REQUIRED TO PROVIDE HOME CARE UNDER SIMILAR CIRCUMSTANCES?

QUESTION FOR DR. CAROLYNE DAVIS
HCFA ADMINISTRATOR

1. DO YOU THINK IT IS FAIR THAT A CHILD WITH A CONDITION IDENTICAL TO LAUREN COOK'S MUST REMAIN IN THE HOSPITAL RATHER THAN RETURN HOME BECAUSE THERE IS NO WAIVER AVAILABLE IN THAT STATE?

QUESTION FOR DR. CAROLYNE DAVIS
HCFA ADMINISTRATOR

2. WE'VE HEARD FROM FAMILIES HERE TODAY OF THE EFFICACY AND DESIRABILITY OF HOME CARE. WE'VE ALSO HEARD HOW DIFFICULT IT IS TO GET COVERAGE. MEDICAID COVERAGE VARIES WIDELY FROM STATE TO STATE. CONSIDERING THE COST-EFFECTIVENESS OF THIS PROGRAM FOR CHILDREN HERE TODAY IS THERE ANY REASON THAT WE SHOULD NOT HAVE A FEDERAL MANDATE THAT ALL MEDICAID PROGRAMS PROVIDE CARE IN THE HOME FOR CHILDREN WHO WOULD OTHERWISE BE INSTITUTIONALIZED?

QUESTION FOR DR. CAROLYNE DAVIS
HCFA ADMINISTRATOR

3. MOST OF THESE FAMILIES TODAY HAVE RELIED ON MEDICAID TO BRING THEIR CHILDREN HOME. THEY HAD PRIVATE INSURANCE, BUT THAT INSURANCE WAS INADEQUATE. IS THERE ANY REASON THAT THERE SHOULD NOT BE A FEDERAL MANDATE REQUIRING PRIVATE INSURANCE COMPANIES TO COVER CARE IN THE HOME THAT THEY COVER IN INSTITUTIONS?

QUESTION FOR DR. VINCENT HUTCHINS

WE HAVE HEARD TESTIMONY TODAY ABOUT THE LACK OF PERSONNEL AND SERVICES NECESSARY TO MAKE HOME CARE WORK FOR THESE CHILDREN. WOULDN'T IT BE A GOOD FEDERAL INVESTMENT TO DEVELOP RESOURCES AND TRAIN PERSONNEL NEEDED?

The CHAIRMAN. Well, I want to thank you, Senator Kennedy.

Senator KENNEDY. I want to thank Ms. Sullivan very much for her work here and for the work on hospice as well. I think that is an extremely important program; we have got similar kinds of problems.

I hope you will come back and tell us about that another time as well as you have described this problem here today. Thank you very much.

Ms. SULLIVAN. Thank you.

The CHAIRMAN. Now that we have broken the ice and you have made such a hit here, we expect you back on a regular basis. [Laughter.]

The CHAIRMAN. Senator Kennedy and I are smitten, I want you to know. Maybe I should not speak for you, Senator Kennedy, but I have a feeling——

Senator KENNEDY. Well, on that occasion, you certainly can. [Laughter.]

The CHAIRMAN. Let me just say this, that we have fought for home health care for the last number of years and we have had some major advancements, but they have not been major enough. In all honesty, we withdraw the home health care bill at the end of last session because we did not have enough time to get it through and we did not have the support of the Office of Management and Budget.

But with that withdrawal, they agreed last year that they will help us to get an appropriate bill through this year, one that takes into consideration all of these factors that Senator Kennedy mentioned and that I have mentioned and that you have mentioned. So we are really going to push hard this year to get a major bill through that will help people just like yourselves, and help families.

I think the important testimony here is not only the children involved, but the families and how important it is; you, Mr. Bachschmidt, your testimony; you, Mr. Cook; you mothers—how much you love these children and how valuable their lives are to you and really to our society.

So, with that, I would like to recess for about 2 minutes just so we can come down and express our regards to you and then we will resume in just 2 minutes. So we will recess for two minutes.

[A brief recess was taken.]

The CHAIRMAN. If we can have order, we would like to continue the hearing. We are running short of time. If we could have your attention, we are so happy to welcome our second panel to the Senate. This panel will consist of several pediatric home health care professionals who can give us some insights based on their personal daily experiences.

Dr. Arthur Kohrman is director of LaRabida Children's Hospital and Research Center and associate professor of pediatrics at the University of Chicago School of Medicine. Mr. Wes Walker is administrative director of physical medicine and rehabilitation at our own Primary Children's Medical Center, and chairman of the Intermountain Health Care Pediatric Home Care Advisory Committee out in my home State of Utah.

Ms. Betsy Davis is vice president for operations of VNS Home Care in New York, and Ms. Liz Ahmann is a nurse practitioner at Children's Hospital of Washington, DC., the home health care department.

Now, I just want to tell you we are honored to have all of you here with us today to share with us your personal experiences with regard to pediatric home health care. We would like you to limit your testimony to 5 minutes each so we have some questions.

I have a tremendous problem this morning because I have another hearing going on just two floors down that I need to get to as well. So I do want to hear all of you if I can, so we will start with you, Dr. Kohrman, first.

STATEMENT OF ARTHUR F. KOHRMAN, DIRECTOR, LARABIDA CHILDREN'S HOSPITAL AND RESEARCH CENTER, AND PROFESSOR AND ASSOCIATED CHAIRMAN OF PEDIATRICS, THE UNIVERSITY OF CHICAGO SCHOOL OF MEDICINE, CHICAGO, ILL; WESLEY P. WALKER, ADMINISTRATIVE DIRECTOR, PHYSICAL MEDICINE AND REHABILITATION, PRIMARY CHILDREN'S MEDICAL CENTER, AND CHAIRMAN, PEDIATRIC HOME CARE ADVISORY COMMITTEE, INTERMOUNTAIN HEALTH CARE HOME HEALTH AGENCY, SALT LAKE CITY, UT; ELIZABETH DAVIS, VICE PRESIDENT OF OPERATIONS, VISITING NURSE SERVICE HOME CARE, NEW YORK, NJ; AND ELIZABETH AHMANN, NURSE PRACTITIONER, HOME CARE PROGRAM, CHILDREN'S HOSPITAL NATIONAL MEDICAL CENTER, WASHINGTON, DC.

Dr. KOHRMAN. Thank you, Senator Hatch. I want to thank you and the committee for the chance to appear here this morning.

The CHAIRMAN. By the way, Dr. Kohrman, and all of you, we will put your full statements in the record as though fully delivered. So if you can summarize, we would appreciate it.

Dr. KOHRMAN. I am happy for the chance to talk to you about my concerns about pediatric home care for children with long-term illnesses and disabilities. The dramatically compromised and yet optimistic children and families we have seen today represent a much larger group whose lives can be made more productive and whose care can be made more rational and less costly through redirection of our systems of medical care and our social institutions.

We must have a firm commitment and support for the concept of helping children to live at home or in other reasonable alternatives to the acute care hospital settings in which so many of them now spend great portions of their lives.

Most of these children will be dependent, at least economically, for many years, if not forever. It is unreasonable and unfair to imagine that in some way they will work themselves out of dependence. They will need outside help for the costs of the complex human services, equipment, and social organizations needed to ensure their best growth and development, which is, after all, our goal.

We must also acknowledge that the problems these children and their families face are often not only perplexing, but somewhat repugnant to us. These children do not always fulfill the dominant image in our society of beautiful, mobile, well-proportioned, articu-

late human beings. They challenge our idealized sense of childhood and the joy with which we want to imagine our young children's lives.

These psychological and social realities, combined with the relatively small numbers of these children and the high costs for their care, together create a very dangerous situation.

These children are exceptionally vulnerable to the vagaries of the political process. Dependent as they are on State and Federal funding and on fluctuations in market forces in the private insurance industry, and without a concerted voice before legislative bodies, there is a great risk that they will be forgotten and buffeted by the uncertainties of politics.

Thus, the central point of my message today is an appeal to the Congress to ensure that not only are programs for these children carefully thought through and put in place, but that this is done in a manner to guarantee that promises made to them in their childhood are fulfilled as they grow and become adult citizens.

If our goal is to give chronically ill children and their families the greatest opportunity for development and productivity, then the cruelest act would be to erect programs which deliver that promise now but fail it later, when public attention is turned to other concerns.

Even now, services for these children and their families are presently very fragmented. Those services which chronically ill and disabled children need most are not traditionally the ones paid for or provided by standard private insurance or governmental programs.

The needs of these children and their families are often not medical, but rather are social and psychological services, access to appropriate ancillary therapies, availability of equipment, and location of competent long-term case management which can intelligently interact with the needs and desires of the child and the family as they grow and change.

Our reimbursement systems are presently almost all oriented toward inpatient hospital care and are focused on payment for physician services and procedures, to the exclusion of the essential nonphysician support services. Most of our programs are institutionally oriented. We are now only beginning to learn how to look outside of our classic institutions to the homes and communities where these children ought to and can reside.

Among the high priorities for children with long-term illnesses and disabilities which must be addressed in new programs and financing mechanisms are the following: First, provision and payment for adequate outpatient and home care services; second, payment for services delivered by other than physicians and nurses acting in traditional roles, such as psychologists, social workers, respiratory therapists, home helpers, and case managers; third, compensation for lost income opportunities for family members; fourth, modification of existing Federal programs, particularly titles XVIII, XIX, and Title V, to make payment available for care in the home. Those program changes will, in turn, provide models and incentives to the private insurance industry; fifth, a series of alternatives to the very expensive and intensive tertiary medical care settings in which many of these children reside for months or even years awaiting movement to less restrictive environments;

sixth, programs which allow for continuous, rational case management either in the hands of well-informed and empowered parents or in conjunction with payors and providers who understand and support the concept of pediatric home care.

There are several concerns that I and other proponents of home care have. These must be remembered as programs are developed and the pediatric home care movement is encouraged. First, we must never allow these programs to be driven by cost or potential cost savings alone. That home care is, in fact, sometimes less costly than hospital care is fortunate; however, the major reason for children being at home is because it is a better place to be for growth and development and for the wholeness of their families.

Second, we must not create programs which become one-way streets; that is, once home care is chosen for a child, that child should not then have difficulty reentering any of the appropriate medical care or other institutions in which benefit might be obtained either on a short- or long-term basis as the child grows, the family changes, or the disease or disability takes on new aspects.

Third, we must be constantly on guard against exploitative entrepreneurialism. Home care may be seen by some as an opportunity for great profit, particularly as inpatient hospital utilization drops and the hospital industry shrinks. Preparation of these children and families for home care and the successful maintenance in the home setting requires meticulous attention with a high degree of professional skill. This planning process is very costly, requiring extensive human resources. It is unlikely that pediatric home care when properly executed can be a fertile field for large profits, which leads directly into my next concern. Fourth, there is an urgent and pressing need for establishment of standards of care, equipment, and continuity in the burgeoning home care industry.

Although the industry itself should begin to develop those standards, both reasons of protection of the patients and their families as well as because of fears of fiscal abuse, it may be necessary for the appropriate governmental agencies to take the initiative in a standard setting. One hopes this can be done in conjunction with the many proven and competent agencies and companies in the private sector.

Finally, we must always maintain our respect for the family's other priorities. Newly revised systems must permit a continuous renegotiation with the families and provide the opportunity for such respite care or other assistance that is necessary to permit the families who care for complex children to attend to their other children, to their work, to their careers, and recreation.

In response to the concerns I have described, I wish to close with several brief proposals addressing the financing and the organization of services to support appropriate pediatric home care. I will be happy to meet and elaborate on these with members of the committee or staff at any time.

First, the ultimate goal of all of us in medicine and all of us as citizens should be the elimination of the conditions, congenital malformations, and diseases which cripple children. This requires continuing basic research and the continued support of the programs of the National Institutes of Health and the other branches of the Federal Government which are directed at the primary prevention

of birth defects, reduction of infant morbidity and mortality, and reduction of environmental hazards to the unborn and developing child. These should continue to have high priority.

Second, I urge new efforts involving HCFA, the Department of Health and Human Services, especially its Division of Maternal and Child Health, and the private and philanthropic sectors in the development of joint demonstration and research projects which will address a number of new issues, including: First, multilevel hospital and institutional care systems. These should include traditional tertiary care, transitional hospital care, and home care or reasonable alternatives to home care so that the chronically ill and disabled child can at any given time be in the most appropriate, least restrictive, most supportive and nurturing, and least costly environment.

Second, out-patient versus in-patient care; demonstration projects should encourage a shift of locus of care into out-patient rather than in-patient settings and allow the appropriate reimbursement of nonphysicians who provide needed services as well as physicians.

Third, different forms of case management and the outcomes and costs of each; demonstration projects should begin to identify the systems which will best ensure continuity of care for the child and family, the maintenance of family integrity and containment of costs.

Fourth, trust funds for the long-term care of our chronically ill and disabled children; we should develop such trust funds, possibly as collaborations between the public, private and philanthropic sectors, in order that all of the payors may benefit from the time value of money invested against future payouts. Of course, such trust fund arrangements must be coupled with active and thoughtful case management. The possibilities here for creative collaboration between providers and payors are truly exciting.

Furthermore, I wish to emphasize the importance of the Title V crippled children's and related programs in the future of care for chronically ill and disabled children. Title V programs are one place where there is convergence of interest both in the organization of services and in the financing opportunities and mechanisms. In addition, the title V programs have a great deal of influence on the directions and inclinations of the private and philanthropic sectors. Where those three can work together, extremely effective programs for chronically ill children can be realized. I would also hope that initiatives to bolster and encourage the role of the title V State agencies will carry with them strong Federal incentives to State legislatures and executives.

I am grateful for the opportunity to address the committee on this very important issue for pediatrics, for parents, for children, and for our society. I am encouraged by your concern and, with you, look forward to the time when we can guarantee that all children will have the same opportunities of growth, development, education, and joy in their homes and families that we all wish for our own.

Children's chronic illness, disability, or even dependency on complex technology should not be barriers to that simple, but profoundly important demonstration of the values of our society.

Thank you very much.

[The prepared statement of Dr. Kohrman follows:]

TESTIMONY

UNITED STATES SENATE

COMMITTEE ON LABOR AND HUMAN RESOURCES

SENATOR ORRIN G. HATCH, CHAIRMAN

JUNE 18, 1985

HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN

ARTHUR F. KOHRMAN, M.D.

LA RABIDA CHILDREN'S HOSPITAL AND RESEARCH CENTER
DEPARTMENT OF PEDIATRICS
THE UNIVERSITY OF CHICAGO
CHICAGO, ILLINOIS

I want to thank you for the opportunity to discuss with you the needs for and my concerns about pediatric home care for children with long-term illnesses and disabilities. The dramatically compromised yet optimistic children and families we have seen today represent a much larger group whose lives can be made more productive and whose care can be made more rational and less costly through re-direction of our systems of medical care and our social institutions. We must have a firm commitment to and support for the concept of helping children to live at home or in other reasonable alternatives to the acute-care hospital settings in which so many of them now spend great portions of their lives.

Most of these children will be at least economically dependent for many years, if not forever. It is unreasonable and unfair to imagine that in some way they will work themselves out of dependence on outside help for the costs of the complex human services, equipment and social organizations needed to insure their best growth and development, which is, after all, our goal. We must also acknowledge that the problems these children and their families face are often not only perplexing but somewhat repugnant to us. These children do not always fulfill the dominant image in our society of beautiful, mobile, well-proportioned, articulate human beings. They challenge our idealized sense of childhood and the joy with which we want to imagine our young children's lives. These psychological and social forces, combined with the relatively small numbers of these children and the high costs for their care, together create a very dangerous situation: these children are exceptionally vulnerable to the vagaries of the political process. Dependent as they are on state and federal funding and on fluctuations in market forces in the private insurance industry, and without a concerted voice before legislative bodies, there is a great risk that they will

be forgotten and buffeted by the uncertainties of politics.

Thus, the central concern of my message today is an appeal to the Congress to insure that not only are programs for these children carefully thought through and put in place, but that this is done in a manner to guarantee that promises made to them in their childhood are fulfilled as they grow and become our adult citizens. If our goal is to give chronically-ill children and their families the greatest opportunity for development and productivity, then the cruelest act we can perform would be to erect programs which deliver that promise now and fail it later, when public attention is turned to other concerns.

Services for these children and their families are presently very fragmented; these services which chronically-ill and disabled children need most are not traditionally the ones paid for or provided by standard private insurance or governmental programs. The needs of these children and their families are less often medical than they are in the areas of social and psychological services, access to appropriate ancillary therapies, availability of equipment, and location of competent forms of long-term case management which can intelligently interract with the needs and desires of the child and the family as they grow and change. Our reimbursement systems are presently almost all oriented toward in-patient hospital care and focused on payment for physician services and procedures, to the exclusion of the essential non-physician support services. Most of our programs are institutionally-oriented; we are now only beginning to learn how to look outside of our classic institutions to the homes and communities where these children ought to and can reside.

Among the high priorities for children with long-term illnesses and disabilities which must be addressed in new programs and financing mechanisms are

the following: first, provision and payment for adequate outpatient and home care services; second, payment for services delivered by others than physicians and nurses acting in traditional roles, such as psychologists, social workers, respiratory therapists, home helpers, and compensation for lost income opportunities for family members; third, provisions for availability of and payment for care in the home through existing federal programs, particularly Title XVIII, Title XIX, and Title V. These program changes will, in turn, provide models and incentives for the private insurance industry; fourth, a series of alternatives to the very expensive and intensive tertiary medical care settings in which many of these children reside for months or even years awaiting movement to less restrictive environments; fifth, programs which allow for continuous, rational case management, either in the hands of well-informed and empowered parents or in conjunction with payors and providers who understand and support the concept of pediatric home care.

There are several concerns that I and others who are proponents of home care have and these must be remembered as programs are developed and the pediatric home care movement is encouraged: First, we must never allow these programs to be driven by cost or potential cost-savings alone; that home care is, in fact, sometimes less costly than hospital care is a fortunate occurrence. However, the major reason for children being at home is because it is a better place to be - for growth and development, and for the intactness of their families; second, we cannot create programs which become "one-way streets"; that is, once home care is chosen for a child, that child should not then have difficulty re-entering any of the appropriate medical care or other institutions in which benefit might be obtained - either on a short- or long-term basis - as the

child grows, or the family changes, or the disease or disability takes on new aspects; third, we must be constantly on guard against exploitative entrepreneurialism. Home care is being seen by some as an aopportunity for great profit, particularly as inpatient hospital utilization drops and the hospital industry shrinks. Preparation of these children and families for home care and their successful maintenance in the home setting requires meticulous attention with a high degree of professional skill. This planning process is very costly in terms of human resources. It is unlikely that pediatric home care, when properly executed, will be a fertile field for large profits; which leads directly into my next concern; fourth, there is an urgent and pressing need for the establishment of standards of care, equipment and continuity in the burgeoning home care industry. It would, of course, be desirable and appropriate for the industry itself to begin to develop those standards. However, both for reasons of protection of the patients and their families as well as because of fears of fiscal abuse, it may be necessary for the appropriate governmental agencies to take the initiative in standard-setting. One hopes that this can be done in conjunction with the many well-intentioned and competent agencies and companies in the private sector already involved in pediatric home care.

Finally, we must always maintain our respect for the families' other priorities. Newly revised systems must permit a continuous renegotiation with the families and provide the opportunity for such respite care or other assistance that is necessary to permit the families who care for complex children to attend to the other children, to their work, their careers and recreation.

I wish to close with several brief proposals concerning financing and organization of services to support appropriate pediatric home care. I have elaborated upon these in my written testimony and will be happy to meet and discuss these with members of the Committee or staff at any time: First, the

ultimate goal of all of us in medicine - and all of us as citizens - should be the elimination of the conditions, congenital malformations and diseases which cripple children. This will only be accomplished through continued basic research and the continued support of the research programs of the National Institutes of Health and in the other branches of the Federal Government which are directed at the primary prevention of birth defects, reduction of infant morbidity and mortality, and reduction of environmental hazards to the unborn and developing child; these should continue to have high priority; second, I urge initiatives involving HCFA, the Department of Health and Human Services - especially its Division of Maternal and Child Health - and the private and philanthropic sectors in the development of joint demonstration and research projects which will address the following:

(a) the development of a multi-level hospital and institutional care system to include tertiary care, transitional hospital care, and home care or reasonable alternatives to home care, so that the chronically-ill and disabled child can, at any given time, be in the least restrictive, most supportive and nurturing and least costly environment appropriate to the child's and family's needs;

(b) demonstration projects which permit attempts to shift the locus of care into out-patient rather than in-patient settings and which allow the appropriate reimbursement of non-physician as well as medical services;

(c) demonstration projects which explore different forms of case management and the outcomes and costs of each, to begin to identify the systems which will insure the best continuity of care for the child

and family, containment of costs, and maintenance of family integrity;

(d) demonstration projects, possibly as collaborations between the private, public and philanthropic sectors, which will explore the possibility of setting up trust funds for the long-term care of our chronically-ill and disabled children in order that all of the payors may benefit from the time value of money invested against future payouts. Such trust fund arrangements must be coupled with active and thoughtful case management; the possibilities here for creative collaborations between providers and payors are exciting.

I also wish to emphasize the importance of the Title V Crippled Children's and related programs in the future of care for chronically-ill and disabled children. Our Title V programs provide the one place where there is convergence of interests both in the organization of services and in the financing opportunities and mechanisms. In addition, in many of our states the Title V programs have a great deal of influence on the directions and inclinations of the private and philanthropic sectors. Where those three can work together, extremely strong programs for chronically-ill children can be realized. I would hope that initiatives to bolster and encourage the role of the Title V state agencies would carry with them strong incentives to state legislatures and executives to work alongside the federal initiatives to bring to fruition the programs which these children and their families so badly need.

I am grateful for the opportunity to address the Committee on this very important issue for pediatrics, for parents, for children, and for our society. I am encouraged by your concern and, with you, look forward to the time when we can guarantee that all children will have the same opportunities of growth, development, education and joy in the midst of their homes and families that we all wish for our own. Children's chronic illness, disability, or even dependency on complex technology should not, in itself, be barriers to that simple - but profoundly important - demonstration of the values of our society.

Senator HAWKINS [presiding]. Thank you, Doctor.

Mr. Walker.

Mr. WALKER. I appreciate this opportunity to share with the committee some of the success we have had with pediatric home health, and also some of the barriers to success that we have experienced as a pediatric home health entity.

Intermountain Health Care is a nonprofit corporation serving 11 States. IHC owns and operates 26 hospitals and affiliates with over 100 hospitals, programs, and services. It also owns the largest home health agency in the State of Utah.

The Primary Children's Medical Center is a member of the IHC family and is a full-service pediatric hospital serving the intermountain West. Like many other well-equipped children's medical centers and hospitals across the United States, Primary Children's possesses the latest in medical technology and life-saving ability.

Children who would have died even a short decade ago are now being saved, but society and modern medicine, with its high technological, life-saving measures, have not kept pace with the programs and resources necessary to medically, as well as socially and emotionally, manage these children once their fragile lives have been saved.

Are we saving these children simply because we have the ability to do so, or do we save them with the commitment to also provide them with a reasonable quality of life? Will these children remain captives of institutional care and an extensive burden to society, or will they, through provision of rehabilitation, home health care and other valuable programs, return to their homes and families to become productive members of society?

Even further behind the pace of medical technology are Government and private insurance reimbursement entities. The inflexibilities of these programs designed primarily to care for the elderly and adult populations leave the needy child and his or her family hopeless and at the whim of costly institutional care.

An example of this inflexibility can be found in the case of baby girl Smith, who was born prematurely just weeks ago at a Salt Lake City hospital. Standing between this infant and the arms of her parents was a 10-day course of IV antibiotic therapy, after which she was to be discharged to home.

IHC Pediatric Home Care was contacted in an effort to get the child home sooner. Medication was to be administered by a home health nurse twice a day, with a cost to Medicaid of about $65 a day for the 10-day course of treatment.

In the State of Utah, twice-a-day home health nursing care is specifically excluded by Medicaid. Therefore, Medicaid elected not to cover the home health care costs for baby girl Smith, who remained in the hospital's newborn intensive care unit at a cost of approximately $150 to $300 per day for the prescribed 10-day course of antibiotic therapy.

This same senseless inflexibility is still experienced on a wide-scale basis. Even though in many instances we find funding for the chronically ill or handicapped children referred to IHC Pediatric Home Care, the parents of many of these children find themselves trapped between the need to provide 24-hour care and the needs of other family members, including themselves.

Funding for respite care is still very scarce indeed either from Government sources or from the private, third-party reimbursement companies. Take, for example, the parents of an infant suffering from bronchopulmonary dysplasia. Their child is home with the support of pediatric home health services, but they are responsible for providing respiratory therapy treatment every 3 hours, 24 hours a day. No respite funding is available.

For pediatric home care to be successful and truly effective, family care givers periodically require time to stand aside in order to regain their perspective on life and the needed strength and endurance necessary to continue this oftimes overbearing responsibility of caring for the chronically ill child at home.

As national pediatric home care policy is developed and adopted, it needs to incorporate reimbursement for respite care.

Seeing the need for development of pediatric home health along the Wasatch Front in Utah, the Primary Children's Medical Center and IHC Home Health Agency developed as a joint venture IHC Pediatric Home Care. The final development combines the strength of an experienced and well-equipped home care organization with pediatric excellence and caring.

Patients typically seen and cared for by our service suffer from bronchopulmonary dysplasia, feeding problems, development delay, and are at risk for neurological impairment. We also see a large number of rehabilitation cases, including severe head trauma.

Our pediatric home care team consists of registered nurses, physical, occupational, speech and respiratory therapists, as well as medical social workers, pharmacists and dieticians, all from pediatric backgrounds.

Medical direction is provided by physicians with pediatric specialities and, of course, the child's own attending physician. Services provided by Pediatric Home Care include skilled nursing, ventilator care, apnea monitoring, hyperalmentation and IV therapy, rehabilitation, hospice care, and others.

The cost of health care for children can be dramatically reduced with the appropriate application of home health care. In fact, cost reduction is the principal motivating factor behind the recent growth in home care interest nationwide.

In the spring of 1984, Primary Children's Medical Center conducted a cost comparison study involving patients in the hospital that could benefit from pediatric home care services. Patients were reviewed from nearly all service areas of the hospital, including infant special care, infectious disease, the medical surgical unit, rehabilitation, hyperalmentation, and patients requiring IV antibiotics, as well as ventilator-dependent children.

As a result of this study, it was estimated that third-party payors combined, including Medicaid, could save as much as $900,000 per year in hospital expenses if these children were involved in home care programs.

Obtaining reimbursement has been an uphill battle and has presented a serious obstacle to the provision of pediatric home health services in our community and State. However, we are now beginning to realize moderate success in dealing with third-party reimbursement as these companies and agencies slowly open their eyes to the benefit of pediatric home health care.

Currently, most children referred for services are approved on a per-case basis for insurance reimbursement. Even though some coverage is available, we still have yet to see the major policy changes necessary to make home health care more readily accessible to chronically ill and handicapped children.

Despite its bleak moments, pediatric home health care has had an overall positive impact on the communities we serve. Take, for example, a very young mother living in a home with no telephone and with a recently discharged at-risk newborn child. When the child experienced respiratory arrest, there was nowhere for the mother to turn for help.

As she watched her newborn dying before her eyes, the home care nurse appeared at the door for her regularly scheduled visit and was able to save the child's life. We have found that it is not an uncommon occurrence for low-income families with at-risk infants and children at home to be unable to afford a telephone. These children are most certainly at greater risk without the ability to communicate with the very sources that may save their lives.

On another occasion, a home health nurse was making a routine call on a family with a child recently released from a newborn intensive care unit with bronchopulmonary dysplasia. She was evaluating the child's respiratory status and discovered something was wrong.

Hospitalization was recommended and, upon hospitalization, a lung abcess was found which could have been life-threatening if left undiscovered and unattended. Apart from the life-saving service rendered by this nurse by being available to detect this serious problem, she saved hundreds of dollars in hospital medical expense by detecting the problem early and limiting the extent of hospitalization.

Another dramatic example of the benefits of home health care is that of Kurtis, a 12-year-old boy who was struck by an automobile while riding his bicycle. Just 1 week prior to his accident, Kurtis had received the Kiwanis Hope of America Award. Now he was hospitalized with multiple injuries, including severe head trauma.

His course of recovery was slow, with little or no improvement from day to day. He was admitted to Primary Children's Rehabilitation Center for intensive therapies, and while his medical condition stabilized, there was still no indication of substantial improvement.

As children typically respond better in familiar surroundings, the decision was made to discharge Kurtis with pediatric home care support. Regular nursing visits, along with consistent physical, speech and occupational therapy, were prescribed. The parents were taught and carried out a therapeutic treatment program.

With many of Kurtis' social and emotional concerns laid to rest by being at home in an environment more familiar, he began to make slow progress. Today, Kurtis is walking, talking and riding his bicycle again. Even though Kurtis now receives his therapies through the hospital's out-patient services, the provision of pediatric home care can be attributed with promoting much of Kurtis' recovery, and at the same time facilitating a much less disruptive family life.

It is also responsible for saving thousands of dollars in intensive in-patient rehabilitation care by enabling early discharge.

In conclusion, as modern medicine continues to expand and develop its life-saving technologies, we must realize that it is not enough simply to save lives, but we must also bear the responsibility of adding quality to the fragile lives that we have spared.

Pediatric home care is a modern health care service with roots that pre-date institutional-based care. It reflects the modern achievements of medical science applied in a practical, sensible and cost-effective fashion. It has been proven to lend much to the stability of families and quality of life of chronically ill and handicapped children.

Pediatric home care is an entity whose time has come, and yet still faces substantial barriers to making it an option more readily available to all those who may benefit from its varied and valuable programs.

I appreciate the committee bringing pediatric home care to light in this fashion and appreciate the opportunity of testifying on behalf of pediatric home health. Thank you.

[The prepared statement of Mr. Walker follows.]

STATEMENT OF

INTERMOUNTAIN HOME HEALTH

PEDIATRIC HOME CARE

AND

PRIMARY CHILDREN'S MEDICAL CENTER

PRESENTED TO:

THE SENATE LABOR AND HUMAN RESOURCES COMMITTEE HEARING

WASHINGTON, D.C.

JUNE 18, 1985

PRESENTED BY:

WESLEY P. WALKER,

ADMINISTRATIVE DIRECTOR OF PHYSICAL MEDICINE AND REHABILITATION

PRIMARY CHILDREN'S MEDICAL CENTER

AND

CHAIRMAN

I.H.C. PEDIATRIC HOME CARE ADVISORY COMMITTEE

DISTINGUISHED SENATORS, MY NAME IS WES WALKER. I AM ADMINISTRATIVE DIRECTOR OF PHYSICAL MEDICINE AND REHABILITATION AT PRIMARY CHILDREN'S MEDICAL CENTER IN SALT LAKE CITY, UTAH AND CHAIRMAN OF THE PEDIATRIC HOME CARE ADVISORY COMMITTEE FOR INTERMOUNTAIN HEALTH CARE HOME HEALTH AGENCY ALSO LOCATED IN SALT LAKE CITY. I APPRECIATE THIS OPPORTUNITY TO SHARE WITH YOU SOME OF OUR SUCCESS AND ALSO SOME OF THE BARRIERS TO SUCCESS THAT WE HAVE EXPERIENCED AS A HOME HEALTH ENTITY.

INTERMOUNTAIN HEALTH CARE IS A NON-PROFIT CORPORATION SERVING 11 WESTERN STATES. I.H.C. OWNS AND OPERATES 26 HOSPITALS AND AFFILIATES WITH OVER 100 HOSPITALS, PROGRAMS AND SERVICES. IT ALSO OWNS THE LARGEST HOME HEALTH AGENCY IN THE STATE OF UTAH.

PRIMARY CHILDREN'S MEDICAL CENTER IS A MEMBER OF THE I.H.C. FAMILY AND IS A FULL SERVICE PEDIATRIC HOSPITAL SERVING THE INTERMOUNTAIN WEST (UTAH, IDAHO, NEVADA, MONTANA, WYOMING, AND PARTS OF COLORADO, NEW MEXICO AND ARIZONA). IT IS THE ONLY FULL SERVICE PEDIATRIC MEDICAL CENTER BETWEEN DENVER AND THE WEST COAST. LIKE MANY OTHER WELL EQUIPPED CHILDREN'S MEDICAL CENTERS AND HOSPITALS ACROSS THE UNITED STATES, PRIMARY CHILDREN'S POSSESSES THE LATEST IN MEDICAL TECHNOLOGY AND LIFE SAVING ABILITY. CHILDREN WHO WOULD HAVE DIED EVEN A SHORT DECADE AGO ARE NOW BEING SAVED. BUT SOCIETY AND MODERN MEDICINE WITH IT'S HIGH TECHNOLOGICAL LIFE SAVING MEASURES HAVE NOT KEPT PACE WITH THE PROGRAMS AND RESOURCES NECESSARY TO MEDICALLY AS WELL AS SOCIALLY AND EMOTIONALLY MANAGE THESE CHILDREN ONCE THEIR FRAGILE LIVES HAVE BEEN SAVED.

I POSE THIS QUESTION: ARE WE SAVING THESE CHILDREN SIMPLY BECAUSE WE HAVE THE ABILITY TO DO SO, OR DO WE SAVE THEM WITH THE COMMITMENT TO ALSO PROVIDE THEM WITH A REASONABLE QUALITY OF LIFE? WILL THESE CHILDREN REMAIN CAPTIVES OF INSTITUTIONAL CARE AND AN EXPENSIVE BURDEN TO SOCIETY OR WILL THEY, THROUGH THE

PROVISION OF REHABILITATION, HOME HEALTH CARE AND OTHER VALUABLE PROGRAMS, RETURN TO THEIR HOMES AND FAMILIES TO BECOME PRODUCTIVE MEMBERS OF SOCIETY?

EVEN FURTHER BEHIND THE PACE OF MEDICAL TECHNOLOGY ARE GOVERNMENT AND PRIVATE INSURANCE REIMBURSEMENT ENTITIES. THE INFLEXIBILITIES OF THESE PROGRAMS, DESIGNED PRIMARILY TO CARE FOR THE ELDERLY AND ADULT POPULATIONS, LEAVE THE NEEDY CHILD AND HIS OR HER FAMILY HOPELESS AND AT THE WHIM OF COSTLY INSTITUTIONAL CARE.

AN EXAMPLE OF THIS INFLEXIBILITY CAN BE FOUND IN THE CASE OF BABY GIRL SMITH, WHO WAS BORN PREMATURELY JUST WEEKS AGO, AT A SALT LAKE CITY HOSPITAL. STANDING BETWEEN THIS INFANT AND THE ARMS OF HER PARENTS WAS A 10 DAY COURSE OF I.V. ANTIBIOTICS AFTER WHICH SHE WAS TO BE DISCHARGED TO HOME. I.H.C. PEDIATRIC HOME CARE WAS CONTACTED IN AN EFFORT TO GET THE CHILD HOME SOONER. MEDICATION WAS TO BE ADMINISTERED BY A HOME HEALTH NURSE TWICE A DAY WITH A COST TO MEDICAID OF ABOUT $65 A DAY FOR THE 10 DAY COURSE OF TREATMENT. IN THE STATE OF UTAH, TWICE A DAY HOME HEALTH NURSING CARE IS SPECIFICALLY EXCLUDED BY MEDICAID. THEREFORE, MEDICAID ELECTED NOT TO COVER HOME HEALTH CARE COSTS FOR BABY GIRL SMITH WHO REMAINED IN THE HOSPITAL'S NEWBORN INTENSIVE CARE UNIT AT A COST OF APPROXIMATELY $300 PER DAY FOR THE PRESCRIBED 10 DAY COURSE OF ANTIBIOTIC THERAPY. THIS SAME SENSELESS FLEXIBILITY IS STILL EXPERIENCED ON A WIDE SCALE BASIS.

EVEN THOUGH, IN MANY INSTANCES, WE FIND FUNDING FOR THE CHRONICALLY ILL OR HANDICAPPED CHILDREN REFERRED TO I.H.C. PEDIATRIC HOME CARE, PARENTS OF MANY OF THESE CHILDREN FIND THEMSELVES TRAPPED BETWEEN THE NEED TO PROVIDE 24 HOUR CARE AND THE NEEDS OF OTHER FAMILY MEMBERS INCLUDING THEMSELVES. FUNDING FOR RESPITE CARE IS STILL VERY SCARCE INDEED, EITHER FROM GOVERNMENT SOURCES OR FROM PRIVATE THIRD PARTY REIMBURSEMENT COMPANIES. TAKE FOR EXAMPLE THE PARENTS OF AN INFANT SUFFERING FROM BRONCHOPULMONARY DYSPLASIA. THEIR CHILD IS HOME WITH THE SUPPORT OF PEDIATRIC HOME HEALTH SERVICES, BUT THEY ARE RESPONSIBLE FOR PROVIDING

RESPIRATORY THERAPY TREATMENT EVERY THREE HOURS, 24 HOURS A DAY. NO RESPITE FUNDING IS AVAILABLE. FOR PEDIATRIC HOME CARE TO BE SUCCESSFUL AND TRULY EFFECTIVE, FAMILY CARE GIVERS PERIODICALLY REQUIRE TIME TO STAND ASIDE IN ORDER TO REGAIN THEIR PERSPECTIVE ON LIFE AND THE NEEDED STRENGTH AND ENDURANCE NECESSARY TO CONTINUE THIS OFTIMES OVERBEARING RESPONSIBILITY OF CARING FOR THE CHRONICALLY ILL CHILD AT HOME. AS NATIONAL PEDIATRIC HOME CARE POLICY IS DEVELOPED AND ADOPTED, IT NEEDS TO INCORPORATE REIMBURSEMENT FOR RESPITE CARE.

SEEING THE NEED FOR DEVELOPMENT OF PEDIATRIC HOME HEALTH ALONG THE WASATCH FRONT IN UTAH, PRIMARY CHILDREN'S MEDICAL CENTER AND I.H.C. HOME HEALTH AGENCY DEVELOPED, AS A JOINT VENTURE, I.H.C. PEDIATRIC HOME CARE. THE FINAL DEVELOPMENT COMBINES THE STRENGTH OF AN EXPERIENCED AND WELL EQUIPPED HOME CARE ORGANIZATION WITH PEDIATRIC EXCELLENCE AND CARING. THE PROGRAM WAS INSTITUTED IN THE FALL OF 1984 AND EVEN THOUGH WE HAVE BEEN IN EXISTENCE LESS THAN ONE YEAR, WE ARE ALREADY RENDERING OVER 100 VISITS PER MONTH IN THE SALT LAKE AREA AND HAVE EXPANDED OUR SERVICES TO THE CENTRAL PART OF THE STATE. PATIENTS TYPICALLY SEEN AND CARED FOR BY OUR SERVICE SUFFER FROM BRONCHOPULMONARY DYSPLASIA, FEEDING PROBLEMS, DEVELOPMENTAL DELAY AND ARE AT RISK FOR NEUROLOGICAL IMPAIRMENT. WE ALSO SEE A LARGE NUMBER OF REHABILITATION CASES INCLUDING CHILDREN WITH MODERATE TO SEVERE HEAD TRAUMA.

OUR PEDIATRIC HOME CARE TEAM CONSISTS OF REGISTERED NURSES, PHYSICAL, OCCUPATIONAL, SPEECH AND RESPIRATORY THERAPISTS AS WELL AS MEDICAL SOCIAL WORKERS, PHARMACISTS, AND DIETITIANS, ALL FROM PEDIATRIC BACKGROUNDS. MEDICAL DIRECTION IS PROVIDED BY PHYSICIANS WITH PEDIATRIC SPECIALTIES, AND OF COURSE THE CHILD'S OWN ATTENDING PHYSICIAN. SERVICES PROVIDED BY PEDIATRIC HOME CARE INCLUDE SKILLED NURSING, VENTILATOR CARE, APNEA MONITORING, HYPERALMENTATION AND I.V. THERAPY, REHABILITATION, HOSPICE CARE AND OTHERS.

PEDIATRIC HOME CARE IS AN INTENSE SERVICE THAT DOES NOT CONTINUE TO SERVE PATIENTS AND FAMILIES OVER AN EXTENDED PERIOD OF TIME. ALL TRAINING PROVIDED BY THE HOME CARE TEAM IS GEARED TOWARD HELPING THE PARENTS LEARN THE SKILLS AND CONFIDENCE NECESSARY IN TENDING TO THEIR CHILD'S UNIQUE MEDICAL AND PSYCHOSOCIAL NEEDS BEYOND THE ACUTE SCOPE OF CARE.

THE COST OF HEALTH CARE FOR CHILDREN CAN BE DRAMATICALLY REDUCED WITH THE APPROPRIATE APPLICATION OF HOME HEALTH CARE. IN FACT, COST REDUCTION IS THE PRINCIPLE MOTIVATING FACTOR BEHIND THE RECENT GROWTH IN HOME CARE INTEREST NATIONWIDE.

THE AMERICAN ASSOCIATION OF RESPIRATORY THERAPY ESTABLISHED THE AVERAGE COST OF CARING FOR A VENTILATOR DEPENDENT CHILD IN THE HOSPITAL AT APPROXIMATELY $271,000 A YEAR. CARING FOR THE SAME CHILD AT HOME WOULD REQUIRE ABOUT $21,000 PER YEAR.

IN THE SPRING OF 1984, PRIMARY CHILDREN'S MEDICAL CENTER CONDUCTED A COST COMPARISON STUDY INVOLVING PATIENTS IN THE HOSPITAL THAT COULD BENEFIT FROM PEDIATRIC HOME CARE SERVICES. PATIENTS WERE REVIEWED FROM NEARLY ALL SERVICE AREAS OF THE HOSPITAL, INCLUDING INFANT SPECIAL CARE, INFECTIOUS DISEASE, THE MEDICAL SURGICAL UNIT, REHABILITATION, HYPERALMENTATION AND PATIENTS REQUIRING HOME I.V. ANTIBIOTICS AS WELL AS VENTILATOR DEPENDENT CHILDREN. AS A RESULT OF THIS STUDY, IT WAS ESTIMATED THAT THIRD PARTY PAYERS COMBINED, INCLUDING MEDICAID, COULD SAVE AS MUCH AS $900,000 PER YEAR IN HOSPITAL EXPENSES IF THESE PATIENTS WERE INVOLVED IN HOME CARE PROGRAMS.

OBTAINING REIMBURSEMENT HAS BEEN AN UPHILL BATTLE AND HAS PRESENTED A SERIOUS OBSTACLE TO THE PROVISION OF PEDIATRIC HOME HEALTH SERVICES IN OUR COMMUNITY AND STATE. HOWEVER, WE ARE NOW BEGINNING TO REALIZE MODERATE SUCCESS IN DEALING WITH THIRD PARTY REIMBURSEMENT AS THESE COMPANIES AND AGENCIES SLOWLY OPEN THEIR EYES

TO THE BENEFIT OF PEDIATRIC HOME HEALTH CARE. CURRENTLY, MOST CHILDREN REFERRED FOR SERVICES ARE APPROVED ON A PER CASE BASIS FOR INSURANCE REIMBURSEMENT. EVEN THOUGH SOME COVERAGE IS AVAILABLE, WE STILL HAVE YET TO SEE THE MAJOR POLICY CHANGES NECESSARY TO MAKE HOME HEALTH CARE MORE READILY ACCESSIBLE TO CHRONICALLY ILL AND HANDICAPPED CHILDREN.

DESPITE IT'S BLEAK MOMENTS, PEDIATRIC HOME CARE HAS HAD AN OVERALL POSITIVE IMPACT ON THE COMMUNITIES WE SERVE. TAKE FOR EXAMPLE A VERY YOUNG MOTHER LIVING IN A HOME WITH NO TELEPHONE AND WITH A RECENTLY DISCHARGED AT RISK NEWBORN CHILD. WHEN THE CHILD EXPERIENCED RESPIRATORY ARREST, THERE WAS NOWHERE FOR THE MOTHER TO TURN FOR HELP. AS SHE WATCHED HER NEWBORN DYING BEFORE HER EYES, THE HOME CARE NURSE APPEARED AT THE DOOR FOR HER REGULARLY SCHEDULED VISIT AND WAS ABLE TO SAVE THE CHILD'S LIFE.

WE HAVE FOUND THAT IT IS NOT AN UNCOMMON OCCURANCE FOR LOW INCOME FAMILIES, WITH AT RISK INFANTS AND CHILDREN AT HOME, TO BE UNABLE TO AFFORD A TELEPHONE. THESE CHILDREN ARE MOST CERTAINLY AT GREATER RISK WITHOUT THE ABILITY TO COMMUNICATE WITH THE VERY SOURCES THAT MAY SAVE THEIR LIVES.

ON ANOTHER OCCASION, A HOME HEALTH NURSE WAS MAKING A ROUTINE CALL ON A FAMILY WITH A CHILD RECENTLY RELEASED FROM A NEWBORN INTENSIVE CARE UNIT WITH BRONCHOPULMONARY DYSPLASIA. SHE WAS EVALUATING THE CHILD'S RESPIRATORY STATUS AND DISCOVERED SOMETHING WAS WRONG. HOSPITALIZATION WAS RECOMMENDED. UPON HOSPITALIZATION, A LUNG ABCESS WAS FOUND, WHICH COULD HAVE BEEN LIFE THREATENING IF LEFT UNDISCOVERED AND UNATTENDED. APART FROM THE LIFE SAVING SERVICE RENDERED BY THIS NURSE, BY BEING AVAILABLE TO DETECT THIS SERIOUS PROBLEM, SHE SAVED HUNDREDS OF DOLLARS IN HOSPITAL MEDICAL EXPENSE BY DETECTING THE PROBLEM EARLY AND LIMITING THE EXTENT OF HOSPITALIZATION.

ANOTHER DRAMATIC EXAMPLE OF THE BENEFITS OF HOME HEALTH CARE IS THAT OF CURTIS, A 12 YEAR OLD BOY WHO WAS STRUCK BY AN AUTOMOBILE WHILE RIDING HIS BICYCLE. JUST ONE WEEK PRIOR TO HIS ACCIDENT, CURTIS HAD RECEIVED THE KIWANIS "HOPE OF AMERICA AWARD". NOW HE WAS HOSPITALIZED WITH MULTIPLE INJURIES INCLUDING SEVERE HEAD TRAUMA. HIS COURSE OF RECOVERY WAS SLOW WITH LITTLE OR NO IMPROVEMENT FROM DAY TO DAY. HE WAS ADMITTED TO PRIMARY CHILDREN'S REHABILITATION CENTER FOR INTENSIVE THERAPIES AND, WHILE HIS MEDICAL CONDITION STABILIZED, THERE WAS STILL NO INDICATION OF SUBSTANTIAL IMPROVEMENT.

AS CHILDREN TYPICALLY RESPOND BETTER IN FAMILIAR SURROUNDINGS, THE DECISION WAS MADE TO DISCHARGE CURTIS WITH PEDIATRIC HOME CARE SUPPORT. REGULAR NURSING VISITS ALONG WITH CONSISTENT PHYSICAL, SPEECH, AND OCCUPATIONAL THERAPY WERE PRESCRIBED. PARENTS WERE TAUGHT AND CARRIED OUT A THERAPEUTIC REGIME.

WITH MANY OF CURTIS' SOCIAL AND EMOTIONAL CONCERNS LAID TO REST BY BEING AT HOME, IN AN ENVIRONMENT MORE FAMILIAR, CURTIS BEGAN TO MAKE SLOW, STEADY PROGRESS. TODAY, CURTIS IS WALKING, TALKING, AND RIDING HIS BICYCLE AGAIN.

EVEN THOUGH CURTIS NOW RECEIVES HIS THERAPIES THROUGH THE HOSPITAL'S OUTPATIENT SERVICES, THE PROVISION OF PEDIATRIC HOME CARE CAN BE ATTRIBUTED WITH PROMOTING MUCH OF CURTIS' RECOVERY AND AT THE SAME TIME FACILITATING A MUCH LESS DISRUPTIVE FAMILY LIFE. IT IS ALSO RESPONSIBLE FOR SAVING THOUSANDS OF DOLLARS IN INTENSIVE INPATIENT REHABILITATION CARE BY ENABLING EARLY DISCHARGE.

IN CONCLUSION, AS MODERN MEDICINE CONTINUES TO EXPAND AND DEVELOP IT'S LIFE SAVING TECHNOLOGIES, WE MUST REALIZE THAT IT IS NOT ENOUGH SIMPLY TO SAVE LIVES, BUT WE MUST ALSO BEAR THE RESPONSIBILITY OF ADDING QUALITY TO THE FRAGILE LIVES THAT WE HAVE SPARED. PEDIATRIC HOME CARE IS A MODERN HEALTH CARE SERVICE WITH ROOTS THAT PREDATE INSTITUTIONAL BASED CARE. IT REFLECTS THE MODERN ACHIEVEMENTS

OF MEDICAL SCIENCE APPLIED IN A PRACTICAL, SENSIBLE AND COST EFFECTIVE FASHION. IT HAS BEEN PROVEN TO LEND MUCH TO THE STABILITY OF FAMILIES AND QUALITY OF LIFE OF CHRONICALLY ILL AND HANDICAPPED CHILDREN. PEDIATRIC HOME HEALTH CARE IS AN ENTITY WHOSE TIME HAS COME AND YET STILL FACES SUBSTANTIAL BARRIERS TO MAKING IT AN OPTION MORE READILY AVAILABLE TO ALL THOSE WHO MAY BENEFIT FROM IT'S VARIED AND VALUABLE PROGRAMS.

I APPRECIATE THE COMMITTEE BRINGING PEDIATRIC HOME CARE TO LIGHT IN THIS FASHION AND APPRECIATE THE OPPORTUNITY OF TESTIFYING ON BEHALF OF PEDIATRIC HOME HEALTH. THANK YOU.

Senator HAWKINS. Thank you.

Ms. Davis.

Ms. DAVIS. Thank you. It is a privilege to be here. I am Betsy Davis and I am vice president of operations of VNS Home Care, a subsidiary of the Visiting Nurse Service of New York, the largest and one of the oldest home health agencies in the country.

Maternal and child health/pediatric services is one of four programs that we offer. You have received my written testimony which I will now attempt to summarize. Specialized maternity and pediatric staff this year will provide approximately 144,000 visits to 14,000 children under the age of 21 in the boroughs of Manhattan, Queens, and the Bronx. This represents approximately an 80 percent increase of services to this age group over the previous year.

The infants, children and adolescents we see have a range of disabling conditions and severe illnesses. They fall probably into four major groups: first, children and infants with birth defects, inherited diseases or some of the problems of prematurity; second, children who are survivors of major accidents or disabling acute illnesses; third, children who are the victims of child abuse; and, fourth, children who are terminally ill.

We see children with diabetes, with cancers of many types, severe cerebral palsy, progressive muscular dystrophy, malnutrition, mental retardation, organic brain damage; children who are the survivors of major devastating accidents; children with liver disease, kidney disease; children with elephant man's disease; children with AIDS disease; children with mental illness, congenital anomalies, amputations, leprosy, rheumatoid arthritis, severe respiratory disease, seizure disorders; children who are physically and emotionally damaged by abuse, and the list could go on.

These children require a variety of mechanical aids and treatments, some with complex, custom-made braces with head pins to support the spine, neck and head to prevent asphyxiation; some with tracheostomies, some with respirators or Hickman broviacs for intravenous nutrition, some with gastrostomies. Some require adaptive feeding chairs, prosthetic limbs, oral prostheses, and a range of developmental equipment.

Many of these children obviously have spent months in the hospital. Once home, these children require constant supervision. Some require 24-hour nursing care, often provided primarily by the family.

The demands, as we know, are not only to provide the physical and emotional care of the child, but to also provide a rehabilitative, educational, and stimulation program adapted to the child's developmental needs and disabilities.

The implications for families are incredible. The mental and physical exhaustion are inevitable. The disruption of the family routine and distraction from relationships with other children within the family create more stress.

Add to all of this the additional financial burdens, already well documented in testimony, and burdens further compounded by the gross inadequacies of health insurance coverage for home care services for children.

Yet, with all of this, families prefer to have their children home. Children do better at home and society benefits. The present fi-

nancing system, however, clearly creates disincentives for families to continue long-term home care of children with severe illnesses or disabilities.

Incredibly, we have created a system that would appear to weaken instead of strengthen the family in its effort to care for a child at home. As a home care administrator, I see the problems of a fragmented, inadequate health insurance program for children creating more difficult barriers for adequate care than for any other population group with which we work.

Last year, our citizen board of directors raised almost $3 million for free care for all of our programs, which include hospice, long-term care, acute care, and our maternal child health/pediatric home care program.

While MCH/pediatric services in our agency represents just 7 percent of our total visits, 50 percent of these charitable dollars supported care for infants and children whose families had no other insurance or means for payment.

Consider for a moment, Sally, a little 8-year-old girl who was in a diabetic coma for 2 months. When she awakened, she was unable to move her limbs or speak, but her eyes followed you around the room.

After 4 months of hospitalization, Sally was discharged home to her parents and siblings. She was totally bedbound, with a feeding tube and a tracheostomy. She was unable to speak or to move.

A coordinated home care program was begun the day of her hospital discharge. This plan included nursing, speech, occupational therapy, physical therapy, and home health aid services.

Now, 15 months later, Sally no longer has any tubes. She is learning to feed herself and slowly she is relearning to speak. The coordination of care and the human dynamics established between her family and herself and her home care professionals and paraprofessionals could not have been realized in the institution.

Had Sally continued to be institutionalized, her care would have cost $280,000. Her home care costs for the last 15 months totaled $22,000. The institutional costs would have been completely covered had she stayed. VNS Home Care subsidized a part of her home care costs until the family was Medicaid-eligible. Her father has recently changed jobs and now part of her care is supported through Blue Cross-Blue Shield insurance.

But more than costs, a home care program for children should be looked on as providing a new type of comprehensive health service based on the preservation of the family and defined health care values, not just as a means of saving institutional costs.

As a society, we have made a conscious choice to continue to promote and to pay for research and technology that help these infants and children survive in the emergency rooms, the intensive care nurseries, and the operating rooms. We spend thousands, sometimes hundreds of thousands of dollars in that initial survival.

It seems to me we have a responsibility to take that survival the next step and to protect that incredible investment in designing an organized acute and long-term care home care program which includes professional and paraprofessional services, includes educational services, includes respite services and other support services in assisting families—and I emphasize assisting families, not taking

over for families, but assisting them as they attempt to meet the children's medical, nursing, emotional, educational needs and promoting the best quality of life possible within a home setting.

I look forward to seeing creative legislation that better supports these amazing children and their families. Thank you very much for this opportunity.

[The prepared statement of Ms. Davis follows:]

Testimony before the

SENATE LABOR AND HUMAN RESOURCES COMMITTEE

June 18, 1985

My name is Elizabeth Davis and I am Vice President of Operations of VNS Home Care, a subsidiary of the Visiting Nurse Service of New York (VNSNY), the largest and one of the oldest voluntary home health agencies in the country. Our mission is and has been to provide home nursing service, other therapies, and support services for the acutely ill, for recovering and dying patients of all ages, as well as for mothers, newborns, and children who are at risk medically or socially.

In 1984, VNS Home Care made over 1,250,000 visits to over 75,000 patients in the Boroughs of Manhattan, Queens and the Bronx through organized programs of Acute Care, Long Term Care, Hospice Care and Maternal Child Health/Pediatric Care. Close to 75,000 visits were made to 10,000 persons under the age of 21 in that same year. 144,000 visits to over 14,000 persons for this age group are projected for 1985.

This growth is just one indicator of the commitment of the Board to the mission of the MCH/Pediatric program and of the broad based support from many organizations and individuals in the community as evidenced by their active participation on the Agency's Professional Advisory Committee. Please see listing of individuals and the organizations they represent attached to this testimony.

In addition, the Board raised funds to bring on expert staff and to establish a comprehensive Educational program for multi-disciplinary teams to meet the needs of sicker and dramatically more disabled children and to provide more support for their families. Also significant are the dollars raised to pay for non-reimbursable home care. Of the $2,700,000 spent last year for free care for the financially disadvantaged in all four programs, <u>half</u> of those dollars supported care for infants and children whose families had no other means for payment. At our current rate in 1985, we would almost double that amount for

subsidized care. We do not have the funds to do so. Table I shows the sources of reimbursement for services for the 6,258 children seen in the first five months of this year.

The infants, children and adolescents we see have a range of disabling conditions and severe illnesses. We see children with diabetes, with cancers of many types, severe cerebral palsy, progressive muscular dystrophy, malnutrition, mental retardation, organic brain damage, children who are survivors of major devastating accidents, children with liver disease, kidney disease, children with neurofibramatosis - better known as Elephant Man's Disease, children with AIDS disease, mental illness, congenital anomalies, amputations, leprosy, rheumatoid arthritis, severe respiratory disease, seizure disorders, children who are physically and emotionally damaged by abuse, and the list could go on... Those children require a variety of mechanical aids and treatments - some with complex, custom-made braces with head pins to support the spine, neck and head to prevent asphyxiation, some with tracheostomies, with respirators or Hickman Broviacs (a central venous catheter into the chest wall) for IV nutrition, some with gastrostomies, some require adaptive feeding chairs, prosthetic limbs, oral prostheses and a range of developmental equipment.

Many of these children are the survivors of our incredible medical and surgical technology. Many have spent months in hospitals, enduring assaultive intrusive procedures. Many require constant supervision; some require 24 hour nursing care, often provided in great part by family members themselves. The demands are not only to provide physical and emotional care of the child, but to also provide a rehabilitative, educational/stimulation program adapted to the individual child and their developmental needs and disabilities.

The implications for the family are incredible, the mental and physical exhaustion are inevitable, the disruption to the family routine and distraction from relationships with other children within the family create more stresses.

Add to all that the additional financial burdens of the direct and indirect costs of caring for an infant or child with severe illness or the lifetime disabilities; a burden often compounded by loss of income of family members who cannot work or have high absenteeism because they are care providers; a burden further compounded by the gross inadequacies of health insurance coverage for home care services: it's a wonder that families endure.

However, with all this, families prefer to have their children at home. Children do better at home, and society benefits. Yet the present financing system clearly creates disincentives for families to continue long term home care of children with severe illnesses or disabilities. While certain professional care services can be reimbursed on a limited basis in some states through Medicaid and some private insurance programs, parents are offered little or no relief from the burden of care either through support services or respite services. Ironically, monetary incentives are there for institutional care or foster home placement. In many states prospective adoptive parents, no matter what their levels of income, are assured of receiving "special" rates to provide care for disabled children until the child reaches 21. In addition, Medicaid eligibility is provided for all these children. However, in striking contrast, children with disabilities living with their natural parents may be eligible to receive SSI payments at levels far below the allowances for these children living with foster or adoptive parents.

Incredibly, we have created a system that would appear to weaken instead of strengthen the family in its effort to care for a child at home. As a home care administrator, the problems of a fragmented, inadequate health insurance program for children create more difficult barriers for adequate care than for any other population group with which we work.

If we were to consider just savings of costs to the system, home care would usually be the setting of choice.

Consider for a moment: Sally, a little 8 year old girl, who was in a diabetic coma for 2 months. When she awakened she was unable to move her limbs or speak, but her eyes were bright as she followed you around the room. After 4 months of hospitalization, Sally was discharged home to her parents and siblings. She was totally bedbound, with a feeding tube and a tracheostomy. She was unable to speak or move. A coordinated home care program was begun the day of her hospital discharge; this plan included nursing, speech, occupational and physical therapy.

Now fifteen months later, Sally no longer has any tubes, she is learning to feed herself, and slowly she is re-learning to speak. Her eyes are still bright and expressive.

The coordination of care and the human dynamics established between her family and herself and her home care professionals could not have been realized in an institution. Had Sally

continued to be institutionalized, her care would have cost 286,200 dollars. Her home care costs for the last 15 months total 22,162 dollars. The institutional costs would have been completely covered, had she stayed. VNS Home Care subsidized part of the home care costs until the family was Medicaid eligible. The father has recently changed jobs and now part of Sally's care is supported through BC/BS insurance.

But more than costs, a home care program for children should be looked at as providing a new type of comprehensive health service based on the preservation of the family and defined health care values, not just as a means of saving institutional costs.

As a society, we have made a conscious choice to continue to promote and pay for the research and technology that helps these infants and children survive in the emergency rooms, the intensive care nurseries, and the operating rooms. We spend thousands, sometimes hundreds of thousands of dollars in that initial survival. It seems to me that we have a responsibility to take that survival the next step and to protect that investment in designing an organized acute and long term care home program which includes professional and paraprofessional services, respite, and other support services in varying degrees in assisting families as they attempt to meet their childrens medical, nursing, emotional and educational needs in promoting the best quality of life possible within a home setting.

The interdisciplinary team model which actively involves families utilized in Hospice has proven extremely effective within our MCH/Pediatric program and could provide a base in developing an organized system of care.

I look forward to seeing creative legislation that better supports these amazing children and their families.

TABLE I
Source of Reimbursement by Case, VNS Home Care
January 1, 1985 - April 30, 1985

	AGE 0	%	AGE 1-5	%	AGE 6-14	%	AGE 15-21	%	TOTAL	%
VOLUNTEER HOSP.	25	1.2%	46	1.9%	17	5.1%	18	1.3%	106	1.7%
MEDICAID	1,064	50.6%	1,619	65.2%	275	82.3%	934	69.8%	3,892	62.2%
BLUE CROSS	14	0.7%	18	0.7%	2	0.6%	7	0.5%	41	0.7%
PRIVATE INSUR.	42	2.0%	20	0.8%	4	1.2%	9	0.7%	75	1.2%
FREE/PART FEE	534	25.4%	521	21.0%	24	7.2%	119	8.9%	1,198	19.1%
PRIVATE PAY	33	1.6%	31	1.2%	12	3.6%	19	1.4%	95	1.5%
HEALTH DEPT.	389	18.5%	230	9.3%	0	0.0%	232	17.3%	851	13.6%
TOTAL	2,101	100.0%	2,485	100.0%	334	100.0%	1,338	100.0%	6,258	100.0%

Senator HAWKINS. Thank you.

Ms. AHMANN. My name is Liz Ahmann. I am a family nurse practitioner. I am writing a book on home care of the high-risk infant. I am director of a local task force on pediatric respite care and I have worked for 3 years in the Home Care Program at Children's Hospital National Medical Center here in the District.

Our Home Care Program is a unique, multidisciplinary pediatric program. It was established in 1981 with funds from the Devore-Stewart Trust. Over the past 3½ years, the Home Care Program has provided nursing, physical and occupational therapy, and social services to 186 children, most of whom have been multihandicapped and very medically involved. Over 75 percent of the families in our caseload have had Medicaid coverage.

The purpose of the Home Care Program has been to facilitate the transition between the hospital and the home and community. Our average length of service has been 6 months, during which time we assist the family to stabilize the child in the home environment, to determine ongoing needs, and to make referrals to appropriate community agencies when possible.

I would like to share with you some of the unique features of our program by illustrating one of our typical cases. We will call the child Jamie. Jamie was born 3 months prematurely. Because of the technological and pharmacological advances we have made in the care of premature infants, Jamie survived many ups and downs in the first months of his life.

At 7 months of age, Jamie went home for the first time. Even then, Jamie went home with multiple problems, including lung disease requiring oxygen, a tracheostomy tube and an apnea monitor. He had feeding problems and very poor growth, a seizure disorder, a complete cleft palate, and developmental delay.

Jamie's parents had been instructed in his complex care needs. They and his 8-year-old sister had rearranged their small apartment to accommodate his medical equipment and supplies. Everyone was excited to have him finally come home.

Jamie was able to go home in part because our Home Care Program was able to provide intensive, home-based nursing, occupational therapy, and social work services. In providing comprehensive care to Jamie and other children like him, we have discovered several important factors, many relating to the need for financial assistance and other issues which the families in the first panel today spoke about.

NO. 1: REIMBURSEMENT SCHEMES

In the care of a multihandicapped, very medically involved child like Jamie, our team members often spend 1 to 1½ hours on each home visit in order to provide a thorough assessment and to address all the problems that can arise.

We are concerned that current reimbursement schemes—that is, a flat fee per visit—do not encourage agencies to take the time needed in home visits to multihandicapped children. We believe that reimbursement schemes need to take into account multiple diagnoses and the complexity of care.

NO. 2: CASE MANAGEMENT

Because our caseload consists of multihandicapped children like Jamie, our team members generally spend an average of 1½ hours per day in case management tasks. We have found case management to be key in ensuring continuity and comprehensiveness of care, as well as cost-effectiveness.

Case management is currently reimbursable under the Katie Beckett waiver, and we believe it should become a standard reimbursable home care service.

NO. 3: SOCIAL WORK SERVICES

The vast majority of the families we have worked with and, in fact, at least 70 percent of all families with chronically ill children, have significant financial problems. Social workers can provide needed assistance in negotiating the maze of benefit programs and in developing funding schemes, as well as providing other psychosocial assistance. We believe social work should be a reimbursable home care service.

NO. 4: RESPITE CARE

As other panelists have discussed, care for a child such as Jamie is very demanding for parents and can place a great strain on the family unit. Our experience indicates that respite care is an essential component of effective home care and is far less costly than rehospitalization.

Respite care is a reimbursable service under the Medicaid home and community-based waiver, but it is not widely available. We believe respite care needs to become easily accessible and a standard reimbursable service.

NO. 5: TRAINING

We have seen a need for training of pediatricians and community health nurses and other health providers in care of the multihandicapped, chronically ill child, particularly related to high-tech care.

NO. 6: COST-EFFECTIVENESS

As other panelists and parents have discussed, we have found home care to be cost-effective. A case in point is a child we will call Mary. With problems very similar to those of Jamie, Mary's hospital bills averaged $62,463 per month. Her home care costs averaged $1,500 per month for the first 4 months, dropping to only $1,000 per month as her condition improved.

Another child we will call Peter had even more complex care and required a ventilator at home. Despite a very costly private duty nursing coverage of 16 hours a day, Peter's home care costs averaged $27,000 less than hospital costs each month.

At the Children's Hospital National Medical Center Home Care Program, we have again and again seen home care to be a cost-effective approach to optimizing the potential of chronically ill and multihandicapped children and their families.

Thank you for the opportunity to discuss this issue and I encourage you to take all the testimony today seriously as you ponder legislation in pediatric home care.

[The prepared statement of Ms. Ahmann follows:]

TO: Committee on Labor and Human Resources
U.S. Senate
FROM: Elizabeth Ahmann, RN,MS,FNP
Re: Pediatric Home Care
(Testimony for hearing 6/18/85)

My name is Liz Ahmann. I am a Family Nurse Practitioner; I am writing a book on home care of the high risk infant; I am director of a local task force on pediatric respite care; and I have worked for three years in the Home Care Program at Children's Hospital National Medical Center here in the District.

Our Home Care Program is a unique multidisciplinary pediatric program. It was established in 1981 with funds from the Devore-Stewart Trust. Over the past 3½ years, the Home Care Program has provided nursing, physical and occupational therapy, and social services to 186 children, most of whom have been multiply handicapped and very medically involved. Over 75% of the families in our caseload have had Medicaid coverage.

The purpose of the Home Care Program has been to facilitate the transition between the hospital and the home and community. Our average length of service has been six months, during which time we assist the family to stabilize the child in the home environment, to determine ongoing needs, and to make referrals to appropriate community agencies when possible.

I would like to share with you some of the unique features of our program by illustrating one of our typical cases - we'll call the child Jamie. Jamie was born 3 months prematurely. Because of the technological and pharmacological advances we've made in the care of premature infants, Jamie survived many ups and downs in the first months of his life. At seven months of age, Jamie went home for the first time. Even then, Jamie went home with multiple problems, including lung disease, requiring oxygen, a tracheostomy tube,and an apnea monitor. He had feeding problems and very poor growth, a seizure disorder, a complete cleft palate, and was develpomentally delayed.

Jamie's parents had been instructed in his complex care needs; they and his 8 year old sister had rearranged their small apartment to accommodate his medical equipment and supplies. Everyone was excited to have him finally come home.

Jamie was able to go home in part because our Home Care Program was able to provide intensive home-based nursing, occupational therapy, and social work services. In providing comprehensive care to Jamie,and other children like him, we have discovered several important factors.

Number One: Reimbursement Schemes

In the care of a multiply handicapped, very medically involved child like Jamie, we often spend 1-1½ hours on each home visit in order to provide a thorough assessment of multiple problems, answer parents' questions, review care as needed, and suggest therapeutic interventions. We have been able to take the time needed on each visit with Jamie because of our foundation funding. Current reimbursement schemes, however, are based on a flat fee per visit. Therefore, home care personnel in an agency dependent on Medicaid or other insurance reimbursement may not find it financially feasable to provide the type of care needed by multihandicapped children. We believe that reimbursement schemes need to take into account multiple diagnoses and the complexity of care.

Number Two: Case Management

Because our caseload consists of multihandicapped children like Jamie, our team members generally spend an average of 1½ hours per day in case management tasks. These tasks include in-hospital pre-discharge consultation; liason with the numerous physicians involved in the care of each child (related to the child's status at home, clinic visits, emergency room visits, and rehospitalizations when necessary); and liason with other community agencies that may be involved with a family, such as educational programs, Medicaid, protective services, a family therapist. These case management tasks are all necessary to promote communication among numerous care providers, and to ensure continuity and comprehensiveness of care as well as cost effectiveness. The REACH project in Florida, funded by the Robert Wood Johnson Foundation and Florida Medicaid, trained nurses to serve as case managers for chronically ill children. Reportedly, after paying the case managers, the program demonstrated a 17% reduction in gross health costs, saving an average of $800 per year per child.By promoting appropriate utilization of services, thus decreasing outpatient procedures and rehospitalizations, case management demonstrated its cost effectiveness. Case management is currently reimbursable under the Katie Beckett Waiver; and we believe it should become a standard reimbursable home care service.

Number Three: Social Work Services

The vast majority of families we have worked with, and in fact, according to Ireys at Vanderbilt, at least 70% of all families with chronically ill children have significant financial problems. A home care social worker can assist families in negotiating the maze of benefit programs and in developing other funding schemes. In addition, chronically ill or disabled children and their families are more likely than their healthy counterparts to have a variety of psychological and social problems. A child's adjustment to chronic impairment, and the ability to function optimally, appear to be related to family functioning. Home based social services, we have seen, can significantly assist in optimizing the functioning of child and family. We believe social work should be a standardly reimbursable home care service.

Number Four: Respite Care

Care for a child such as Jamie is very demanding and can place a great strain on the entire family unit.In a Robert Wood Johnson Foundation funded study of the Home Care Program population, families were asked what helped them care for their children at home; a strong theme that emerged was the need to have people share the actual caretaking of the child. Based on limited surveys in the District, funded by the Association for the Care of Children's Health and the April Trust, a minimum of 450 families of children with chronic illness in D.C. alone feel a need for respite care. The Vanderbilt study also supports the need for respite care. Joyce,et al, in a 1983 study of families participating in an in-home respite program, found that 30% of the parents would definately be unable to care for their disabled children at home without respite and 88% felt that the service significantly aided them in avoiding institutionalization of their children. Cohen, in a 1981 study, found that families receiving respite care evidenced significantly better attitudes toward the disabled child, better ability to cope with the child in the home, and better family functioning, satisfaction with life and hopefulness for the future than did comparable families not receiving respite.

In many communities respite care is available for the mentally retarded and developmentally disabled, but not for children with chronic illness. For these families, respite is exceedingly difficult to obtain.

Depending on the child's condition and the family's needs, appropriate respite care can take a variety of forms. Respite care might be needed for an occasional break (for example, for a parent's own medical appointment); for several hours or afternoons a week for parental relief and time for the family to relax together; or for occasional weekend or week-long coverage to allow family vacations. Respite care might most appropriately be provided in the family's home, someone elses home, or in an institution. Respite care might most appropriately be provided by a trained lay person, a health aide, or a professional nurse, depending on the child's condition.

Our experience indicates that respite care, in whatever form is most appropriate, is an essential component of effective home care; and, respite is far less costly than rehospitalization. Respite care is a reimbursable service under the Medicaid Home and Community Based Waiver, but is not widely available for the chronically ill. We believe that respite care needs to become easily accessible and a standard reimbursable service.

Number Five: Training and Research

We have seen that to ensure safe, effective and comprehensive pediatric home care, severalissues must be addressed. Community pediatricians need training that will increase their expertise and comfort in providing primary care for the increasing population of children with multiple and complex impairments. Community health, and other,nurses providing home care services to children should have pediatric training and need ongoing, updated training programs that address care of the child with high tech care needs. Training in family intervention and in recognizing signs of child abuse and neglect is important for all home care personnel.

Research about pediatric home care is needed. Ruth Stein, at Albert Einstein-Bronx Municipal Hospital has begun to study child and family factors that may predict the eppropriateness of home care services. Further study should be encouraged in the areas of evaluating appropriate hospital discharge planning and in determining what makes home care work for which children and families.

Number Six: Cost Effectiveness

We have found home care to be cost effective. A case in point is a child we'll call Mary. With problems similar to those of Jamie,Mary's hospital bills averaged $62,463 per month, or over $2000 per day. Her home care costs averaged $1500 per month for the first four months, dropping to only $1000 per month, or $33 per day, as her condition improved. Another child we'll call Peter was born with a rare neuromuscular disease making it difficult for him to move his arms and legs and to breathe without the assistance of a ventilator. Peter's monthly hospital charges averaged over $40,000 per month. Home care costs for Peter (including equipment and supplies, formula, medications, transportation, clinic visits, increased home electrical bills, the services of our program, and 16 hours of skilled nursing each day at home) have averaged $13408 per month: a savings of $ 27000 per month over hospital costs, each month.

Numerous other programs have also shown home care to be cost effective. Yet, a 1983 Pennsylvania Health Department study (reported in CARING, May,1985) found that 260 ventilator dependent individuals under the age of 21 were in hospitals, unable to go home because they could not find reimbursement for home care. The cost of care for these individuals totalled approximately $93.6 million per year. Home care for the same individuals would have cost approximately $3.12 million, thus saving over $90 million each year in Pennsylvania alone. Clearly, home care is cost effective.

At the Children's Hospital National Medical Center Home Care Program, we have again and again seen home care to be a comprehensive approach to optimizing the potential of chronically ill and multihandicapped children. We have seen home care, in fact, benefit the entire family. The field of pediatric home care is a growing field. It is growing because children and families need it to grow. Federal legislation must reflect the needs of chronically ill children and their families in this very important area.

Senator HAWKINS. Thank you very much; a very interesting panel.

I have a prepared statement which I would like to insert in the record at this point.

[The prepared statement of Senator Hawkins follows:]

STATEMENT OF SENATOR PAULA HAWKINS

ON

HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN

Mr. Chairman, It is hard to imagine a more frustrating situation than a parent who wants to be near and personally help care for their critically ill child but is prevented from doing so because of the provisions in public and private health insurance programs.

Unfortunately that is the situation facing millions of chronically ill children today. Our methods of paying for health care for these children forces many parents to suffer through needless trauma and separation despite the fact that the technology that keeps these children alive is flexible enough to allow them to be cared for in their own homes.

I don't want in any way to be perceived as being critical of the fantastic care that these children receive in hospitals. The doctors and nurses who care for these children are dedicated to these children's survival. But interestingly enough, it is often

these health professionals that are among the first to agree that these chronically ill children need the love, attention and special care that only their own families can provide.

Often it takes the dramatic example of one child, and one dedicated family to propel Congress, the Administration and the States into long overdue action. In this situation, it took the heart-rendering tale of Katie Beckett to prompt the Administration to propose and the Congress to enact a provision permitting the States to apply for a Medicaid waiver for home and community based care for chronically ill children. I am delighted to see Katie here today. She has obviously blossomed under the loving care of her parents. I hope that Katie's story and the stories of Brandon, Robert and Lauren will prompt more States to participate in this waiver program and encourage the States who are already participating to improve their programs to better serve this special children.

Senator HAWKINS. Dr. Kohrman, you have expressed concern about fraud in the home care industry. How can unscrupulous entrepreneurs best be prevented from exploiting these sick children and their families?

Dr. KOHRMAN. I am not as concerned about outright fraud as I am about irresponsibility. You have just heard very eloquently how meticulous and expensive in human resources preparation for home care is.

As the director of a hospital, I get up to three notices a week of a new home health care agency springing up in the Chicago area. Many of these are simply individuals declaring themselves to be home health care agencies, who hope to be reimbursed under whatever reimbursement mechanism exist but who are in no way qualified to develop this kind of a meticulous program. I am much more concerned about that.

My reference to fraud and abuse was because I think the Congress and the regulatory agencies, particularly HCFA, are appropriately concerned about maintaining control over the funds they administer. We are all very aware of some abuses in some Federal programs; I wanted mostly to signal my recognition of that concern, and to recognize that whatever programs are developed, that in this kind of a burgeoning industry there are going to be some fringe activities, as with Medicaid and others.

I do not think that the abuses invalidate the programs, but I do think that those of us who are responsible should recognize the need to build safeguards in as we develop new programs.

Senator HAWKINS. You proposed a new trust fund for chronically ill children. Do you think the expenditures could be contained by a prospective or capped payment mechanism?

Dr. KOHRMAN. There is a significant difference between prospective and capped, I do not want to answer both of those simultaneously. Let me take the first; there is a significant time value of money, and my insurance industry colleagues have pointed out to me that if you have $1 million indemnity that has to be payed anyhow under a major medical policy, and if the payout on that can be extended from, say, 2 years, to 20 years, you buy annuities for that $1 million something, over $600,000.

The difference between the purchase price of those annuities and the actual indemnity of the company represents cost savings, which then could be significantly applied to the care of these children and the maintenance of a trust fund.

I would be very anxious to see some kind of private-public venture, possibly initiated by HCFA research and demonstration projects, that will begin to explore the possibility of purchasing annuities or setting up trusts for each of these children as they enter the system in anticipation of the future payouts. I think there might be significant savings for all involved, Senator Hawkins.

Senator HAWKINS. Thank you.

Mr. Walker, some critics of home health care say if the services are expanded that the care provided by the families would simply be replaced by very expensive teams. In your experience, have families abandoned their responsibility to home care professionals?

Mr. WALKER. Our experience has been that the families have been most supportive and most willing to assume as much care of

their child as possible, once they have been taught by the home care team how to do that.

It is not our intent as a pediatric home care agency to provide care forever for these families. Rather, we attempt to wean them off of dependency on the home care team as time goes by and they are able to learn and pick up and instigate treatment themselves.

Senator HAWKINS. Thank you.

Ms. Davis, the visiting nurse associations are known to provide excellent home care. What efforts by visiting nurses do you know of to help families assume responsibility for basic health care?

Ms. DAVIS. I am sorry; I missed the last part of that question.

Senator HAWKINS. We know that the visiting nurse associations provide excellent care in the best traditions of public health. What responsibilities or efforts are being assumed by the visiting nurses associations to help families assume the responsibility for basic home health care?

Ms. DAVIS. What we are attempting to do is create coordinated team approaches to health care which very actively involve the family and the patient. One of the models that we have begun to build on in maternal child health is the hospice model of coordinated team care, with the family assuming a very predominant role.

Now, if your question is also in reference to preventive services, VNA's are also concerned about the issues of immunization, of nutrition, of more adequate prenatal care. We know in New York State, for example, and particularly New York City, that the inadequacy of prenatal care and poor nutrition are more the problems that can lead to prematurity and low birth weight infants.

Part of our role is to work with other agencies and with health departments in a coordinated way to offer a range of services

For example, right now we have a special project with Harlem Hospital to work with teenage women who have had children and are attempting to raise those children and need help in basic preventive skills, nutrition and so forth.

Our role is multifaceted. It includes primary prevention, education, fostering good nutrition, as well as the provision of treatment services. It is also to offer a coordinated team approach involving families in managing their own care. We do offer a range, from prevention all the way through terminal illness care.

Senator HAWKINS. How does the income of a visiting nurse compare to that of a hospital nurse?

Ms. DAVIS. Their individual salaries, you are referring to?

Senator HAWKINS. Yes.

Ms. DAVIS. They are comparable. In New York City we attempt to have our salaries be slightly above the hospital nurses in order to recruit staff and in recognition of the kind of responsibility they has. Some of the issues for us, particularly in New York City, are the need to provide services in unsafe areas. We have escort services for staff in the high-crime, high-drug areas. Safety issues sometimes makes our recruitment a little more difficult.

Senator HAWKINS. Is there enough difference to make home nursing attractive to nurses?

Ms. DAVIS. Salary may be a part of the attraction, although in some States we known that salaries of community nurses may not comparable to hospital nurses. The people who are attracted into

home nursing are also people who need to function independently, have sound judgment, are able to work in a coordinated way, and are able to draw on community resources.

I think one of the things we value particularly as a VNA is our ability to use other resources to help families—for example, church groups—which was draw upon to provide support during a terminal illness. They may even provide 24-hours assistance.

So the kind of work that attracts this kind of nurse has some differences than that seen in a hospital. We do have to offer intensive training for our staff, particularly in this whole area now of high-tech services. And we have added specialty staff—pediatric nurse practitioners as well as physicians and psychologists—in our Maternal Child Health Program, and do offer a 24-hour service. Community nursing has it unique fractures and it does require updating and on-going education.

We do attract some staff from hospitals who have worked in intensive care nurseries. They are interested in trying to move that kind of care out into the communities.

Senator HAWKINS. Thank you.

Ms. Ahmann, who should do case management? Should that be a new type of professional or is it the home care nurse? Is it the social worker?

Ms. AHMANN. This is a very good question, and I think one issue is that more research needs to be done to look at the best case management approaches. On our team, the professsionals involved in providing direct services have taken on the case management role.

For example, if the child's major problems are medical nursing, a nurse will be the case manager. If the child's major problems are rehabilitation and therapeutic in nature, the physical or occupational therapist will be a case manager, and so on.

I know there are other programs that are proposing to provide solely case management services and not direct services. I am not personally as familiar with those, but I think that it would be important to look into different schemes and have some evaluation of the most optimal approach to case management.

Senator HAWKINS. As we expand home care services, do we run the risk of complicating the current system if the number of care givers is expanded?

Ms. AHMANN. Could you repeat that? I did not hear the entire question.

Senator HAWKINS. As we expand home care services, will we complicate the current system if we have more options in the number of care givers?

Ms. AHMANN. Could you clarify what you mean by the current system?

Senator HAWKINS. Well, whoever does it now.

Ms. AHMANN. The current home care system?

Senator HAWKINS. Yes.

Ms. AHMANN. I think to some extent the current services being provided to families do include the services that I have talked about. The reimbursement schemes do not always make those services available. Is this what you are referring to?

Senator HAWKINS. Yes.

Ms. AHMANN. I think that we will not complicate the care provided by making available reimbursement for case management, making more widely available respite care, making more widely available reimbursement for a variety of social work functions.

I think that we will be providing the care that innovative programs have already provided and have shown that families actually do need in the home.

Senator HAWKINS. Senator Dodd, this is the conclusion of our second panel.

Senator Dodd has joined us. We welcome you.

Senator DODD. Thank you very much, Madam Chairman, and let me apologize to the first panel for not being present during your testimony. I appreciate the witnesses being here, particularly the children, this morning.

Madam Chairman, I have an opening statement which I would ask unanimous consent be made a part of the record, if I could.

Senator HAWKINS. Without objection.

[The prepared statement of Senator Dodd follows:]

STATEMENT OF SENATOR CHRISTOPHER J. DODD
LABOR AND HUMAN RESOURCES COMMITTEE
JUNE 18, 1985

I WOULD LIKE TO THANK THE DISTINGUISHED CHAIRMAN AND RANKING MINORITY MEMBER OF OUR COMMITTEE FOR ORGANIZING TODAY'S HEARING ON HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN. THIS IS A VITALLY IMPORTANT ISSUE NOT ONLY FOR THE COURAGEOUS CHILDREN AND FAMILIES REPRESENTED HERE TODAY, BUT FOR THE MILLIONS OF CHRONICALLY ILL CHILDREN THROUGHOUT OUR NATION. INDEED, BECAUSE WE WILL BE CONSIDERING PRIVATE AND PUBLIC POLICIES WHICH ALSO AFFECT HOME CARE FOR THE ELDERLY, THE TERMINALLY ILL, AND OTHERS, TODAY'S HEARING CAN HELP PROVIDE A CONCEPTUAL FRAMEWORK FOR THE DEVELOPMENT OF COMPREHENSIVE NATIONAL POLICY IN THIS AREA.

OVER THE PAST FEW YEARS, HOME HEALTH CARE HAS PROVEN TO BE A HUMANE, RESPONSIBLE, AND COST-EFFECTIVE ALTERNATIVE TO HOSPITALIZATION AND OTHER FORMS OF INSTITUTIONALIZED CARE. AS SEVERAL OF OUR WITNESSES WILL INDICATE HERE TODAY, MANY IF NOT MOST CHRONICALLY ILL CHILDREN CAN BE TREATED SAFELY AND MORE INEXPENSIVELY IN THE HOME ENVIRONMENT. WHILE THESE CHILDREN OFTEN DO NEED COMPLICATED MEDICAL AND THERAPEUTIC SERVICES, RECENT ADVANCEMENTS HAVE MADE IT POSSIBLE TO PROVIDE SUCH CARE AT HOME. MOREOVER, CHRONICALLY ILL CHILDREN TYPICALLY RESPOND BETTER TO THERAPY IN THE FAMILIAR AND COMFORTABLE HOME ENVIRONMENT, THANKS TO THE LOVE AND NURTURING WHICH ONLY PARENTS CAN PROVIDE. IN MY VIEW, IT MAKES LITTLE SENSE TO HOSPITALIZE OR INSTITUTIONALIZE A

CHRONICALLY ILL CHILD WHEN SAFE AND COST-EFFECTIVE HOME CARE IS ALSO AVAILABLE.

UNFORTUNATELY, IN TOO MANY CASES, PUBLIC AND PRIVATE REIMBURSEMENT POLICIES EFFECTIVELY RULE OUT THE HOME CARE OPTION EVEN WHERE THE SAME CARE WOULD BE COVERED IN AN INSTITUTIONALIZED SETTING. AND YET, WITHOUT SOME FORM OF FINANCIAL ASSISTANCE , NO FAMILY CAN AFFORD TO PROVIDE THE CARE AND SUPERVISION NECESSARY TO SUSTAIN A CHRONICALLY ILL CHILD AT HOME. THE UNWANTED RESULT IS THAT MANY FAMILIES HAVE TO MOVE FROM STATE TO STATE, PARENTS HAVE TO CHANGE JOBS, AND CHILDREN HAVE TO BE MOVED FROM ONE INSTITUTION TO ANOTHER, SIMPLY TO GET THE FINANCIAL ASSISTANCE AND SUPPORT FOR HOME CARE SERVICES WHICH THEY NEED AND DESERVE.

THE LIVES OF CHRONICALLY ILL CHILDREN AND THEIR PARENTS ARE DIFFICULT ENOUGH WITHOUT HAVING TO FACE THE UNNECESSARY HARDSHIPS CREATED BY THESE RESTRICTIVE AND ANTIQUATED REIMBURSEMENT POLICIES. I BELIEVE THAT FEDERAL POLICY IN THIS AREA CAN HELP TO ASSURE THAT QUALITY HOME CARE IS AVAILABLE TO THESE CHILDREN, WITHOUT REQUIRING OF THEIR FAMILIES THE UNREASONABLE SACRIFICES WHICH SEVERAL OF OUR WITNESSES HAVE HAD TO ENDURE. I HOPE THE DIALOGUE ESTABLISHED DURING TODAY'S HEARING WILL HELP GUIDE US AND OTHER PUBLIC POLICY MAKERS TOWARD THE REALIZATION OF THIS GOAL.

Senator DODD. Let me just paraphrase some of my own thoughts on this. First of all, I commend the committee for holding this hearing because it is an issue that there should not be a great deal of debate on, at least when it comes to the conclusion.

It seems to me we have drawn that conclusion in a number of instances; the Ronald McDonald Houses, for instance. We just opened up another one in New Haven, CT, which I was pleased to be at the ribbon-cutting ceremony for.

The notion of families being with their children in times of crises is one that we have endorsed at that level. I am on the board of directors of a group of people that the chairperson knows well, the Alpha and Omega family of Connecticut and the Rosseau family, which have adopted critically children—mentally retarded, and so forth—and maintained them in a home environment.

Even though these are adopted children not with their parents, and so forth, maintaining the home environment has, without any question, made it possible for these children to live far fuller lives than they ever would have. In fact, in most cases I suspect that they would not have lived at all.

So, again, the conclusion of providing that kind of a setting, it seems to me, we have already decided makes a lot of sense, and the question now really becomes how do we make it possible for families that do not have the resources of a private foundation that can afford the kinds of care that these children are receiving.

Let me ask you, if I can, Dr. Kohrman and Mr. Walker, I guess, particularly at the outset, we seem to have kept more than apace with the technology of how to keep a child alive—last week, the septuplets in California where the whole Nation was riveted for a week watching that story unfold, and the loss of several of those infants and the technology that managed to save the lives of several of them who are now heading home, I guess, or will be shortly. A couple of those children--one of them may end up being a critically ill child.

I suspect there will be nowhere near the attention on what happens to those children once they are home that there was when they were in the hospital. I am not criticizing the fact that we have done a lot to keep these children alive, but have we not managed to maintain the same kind of cutting edge, state-of-the-art, if you will, technology in home care for critically ill children that we have to keep them alive in the first place?

It seems to be a contradiction. Explain that.

Dr. KOHRMAN. It is a very complicated answer and I am not sure I know the whole answer. Part of it, I think, has to do with something I mentioned in my testimony. These children do not fulfill our visions of idealized childhood. They are not always pretty and bright and mobile.

Some of the psychological and social factors are not different from those that affect the handicapped and disabled in general, who have only been recently "let out of the closet," within our own adult lifetimes.

I think the second issue and one that you touched on is very important: there has not been attention to the development of simple technology for the care of people at home. We all have a technophi-

lia; we are very excited about the dramatic high-intensity technology that keeps these people alive.

One of the reasons, of course, is—and I hate to sound cynical, but I think it is true—that there is no market for that simpler equipment. There is not much incentive to development low-tech, simple, easily reparable, low-volume equipment for the support of people at home because, frankly, there is no profit in it.

And as I have stated in my written testimony, I think the Congress may very well have to deal with that problem in the same way it did with the Orphan Drug Act. You may have to provide some incentives for development of that simpler technology, because there is not a large enough commercial market for it to be highly profitable.

I would also commend to your attention, in that regard, a recent OTA report, "Technology and Handicapped Persons" that pinpoints these issues in technology development.

The third issue is that we are fundamentally a mediagenic society, and what goes on in the day-to-day lives of these kids is neither very media exciting nor is it very attractive nor does it have those kinds of peaks that seem to attract our attention.

As we heard this morning, it is a slow, plodding, daily, grinding process both for the children and particularly for their families; there is not much you can talk about in a 10-second snatch on the evening news.

Senator DODD. Well, we know that, painfully.

Mr. Walker, do you want to comment?

Mr. WALKER. I would agree totally with what Dr. Kohrman has mentioned here about the simplified equipment necessary to care for these children at home. I might add to that that even though there is technology to save children's lives, the very technology that does save their lives often causes the problems that we deal with in a home care situation—for example, the bronchopulmonary dysplasia problem created in a newborn intensive care unit by overoxygenization, caused by the ventilation systems, in combination with the premature condition of the child.

But I think by and large the problems that we experience in our agency with high technology are a result of the need for simplified equipment that families can learn to run themselves at home that is not as costly as the large respiratory units, for example, that you would find in a hospital setting.

Senator DODD. Let me ask our two witnesses here something, and any of you can comment on this. If you want to pick up on this first question, I would ask you to comment on that as well if you would like.

Today, we are focusing on reimbursement and I would like to know, in addition to doctors, and so forth, what is reimbursable to these families. But another part of the question is a lot of times, it seems to me, we focus on those kinds of questions and not the kind of questions where existing resources are available, what efforts are made to reach out, to make sure that people are aware of what is available to them in a community.

How much investment is made in that part of the program, to the extent that you may argue that these are not adequate reimbursements? Are they being taken advantage of, to the extent they

exist, by people who have families that have these kinds of situations, and if not, why not?

Ms. DAVIS. I think the complications of working through the system are the major barriers for families. The families that we have heard from this morning are obviously very competent, persistent, well put together, and are able to manage and work through the system.

Senator DODD. Right.

Ms. DAVIS. We find one of our major jobs as visiting nurses, is to try to act on behalf of families when they do not have the capacity to do that.

Particularly complicated sometimes are the single-parent families, who also have some of these very disabled, ill children and who are trying to also manage them at home. So part of our job is to improve access to and information from the health and welfare system.

We feel that network building is a very important part of our services for these children. Our professional advisory committee has representatives from approximately 25 or 30 other organizations representing interests and concerns of mothers and children who are active in New York City and who provide valuable resources.

The financial barriers are difficult to overcome. While we have certain advantages in New York City through the Medicaid Program, the process and the forms that have to be filled out, the appearances tha families have to make at the welfare office in order to gain those services—becomes very complex and very time consuming.

Private insurance coverage—you have to go to an insurance company and be able to prove that your services will cost less, and again that takes a highly motivated, able family to do that. We do have to function on behalf of some of our families.

We haven't made much progress in private insurance coverage for these childen. Less than 2 percent of what we provide in our Maternal-Child Health Program is covered through private insurance.

As health care providers, one of our major tasks is to try to put together these resources, build networks in order to help families access these services more readily.

Senator DODD. Well, is that being done? I mean, you just described a process very quickly that sounds to me like the average person would goes bonkers trying to figure that one out.

Ms. DAVIS. Right. Our staff also goes bonkers in trying to work through that system as well. It is being done and I think gains are being made. We are finding that in the city of New York that the Medicaid process is being simplified. The system has been reorganized partly at least in response to recognizing the value of moving children and adults outside of institutions and trying to maintain them in their homes.

I think progress is being made. I saw one 12-page form that we used to have to fill out for Medicaid-eligibility that has been reduced to four pages. That is a major accomplishment.

Senator DODD. This is in New York?

Ms. DAVIS. Yes.

Senator DODD. Is that going on in other states as well?

Ms. DAVIS. I am also recently from the state of Vermont. I know there, that the funding for Medicaid for home care of these children is very difficult. It is inadequate and the resources are not enough to provide the care at home for these very disabled children.

I think it is happening to a lesser degree in other States in the country than perhaps in New York.

Ms. AHMANN. I have several comments in response to both of your questions.

Senator DODD. Yes.

Ms. AHMANN. With regard to the first issue you raised on why are we not more aware of the problems of children at home, I agree with the comments the other panelists made, and I would also like to add that there are many children who still are not able to be at home with their chronic disabilities in large part because of reimbursement and funding difficulties.

I think the latest issue of Caring, May 1985, the journal of the National Association of Home Care, had a report on a study in Pennsylvania. Over 100 childen under the age of 21 were remaining in hospitals; they could have been provided care at home, but it had been impossible to figure out funding schemes to get them home. I think that study was in 1983.

The cost savings, if they had been at home, would have been, incredible—some $90 million in the State of Pennsylvania alone. Yet, the numbers of children going home with multiple and very complex problems is still small because the barriers, financial in particular, to getting them home are very high.

You also asked about available community resources and whether these are being used. In large part, the programs that I am familiar with that are assisting children and families in the home environment make wide use of networking and a variety of community resources.

There is a problem, though, that some of the resources that families most need are hard to access, may be relatively unavailable, and are difficult to fund. Some of those kinds of services would be case management, which is one role that health care providers can take in terms of helping families access programs, but case management is not a standard reimbursable service.

Respite care is relatively inaccessible and unavailable for chronically ill children. Some educational services are lacking. Social work services are reimbursable only for certain types of problems.

So one problem that we have to look at is how to make available the kinds of services that these families need, and when they are available how to help families access them.

Senator DODD. Thank you. Yes; Doctor, you wanted to comment.

Dr. KOHRMAN. Yes. I would like to make two important comments that should not be lost from the record. I am, as all of you, in awe of the competencies and the accomplishments of the parents we see here with us today.

Seventy percent of my clients—I run one of the few hospitals for chronically ill children in the United States—are one-parent families. The problems that the families we have seen today face and

have overcome are absolutely insoluble for most families in the inner city of Chicago, New York, Los Angeles, or Washington.

There is a very important connection between poverty and the problems we are seeing; we cannot let that escape from these hearings. The urgent fact is that the single largest group of new technology-dependent children coming into the system are the products of extreme prematurity and very low birth weight; those are problems of the inner city and of the poor in our country.

So we can anticipate that the greater burden is going to be on those families with the least resources to cope with it. Thus it is not sufficient to use these idealized situations as the models on which to look at legislation.

The second point that I want to make, of equal importance, is related to the issue of rationalization of existing resources. There are many under utilized resources in our health system; I am sure the Senate and this committee are very aware of overcapitalization in the hospital industry and maldistribution of the resources we have.

I would like to emphasize the need to look at regionalization of our existing resources and the development of a series of stepped resources so the children can be where they need to be.

We need not only the tertiary care, intense hospitals. We need transitional care resources, group home resources, and respite care resources, which can be organized in a way that will distribute the costs and the care more appropriately to the needs of the child and the family at the time, rather than distributing them all, as has been traditional, into our major hospitals, which are the most costly part of the system. I would urge that any legislation look at that distribution as well.

Thank you.

Senator DODD. Thank you very, very much.

Senator NICKLES [presiding]. Thank you, Senator Dodd.

Senator Pell, did you have any comments or questions?

Senator PELL. Thank you very much, Mr. Chairman. I would like to congratulate the chairman of the committee and the members of the majority side who are conducting this hearing.

We all know that costs, both the financial and the emotional costs, of hospital care and institutional care are astronomical. I am looking forward to reading what I have not heard from these witnesses as to how these high costs can be reduced.

In this regard, at this time I would ask that the full text of my statement be inserted into the record as if read.

Senator NICKLES. Thank you, Senator Pell. It will be.

[The prepared statement of Senator Pell follows:]

PREPARED STATEMENT BY SENATOR CLAIBORNE PELL

Mr. Chairman, I would like to commend you for convening this hearing to focus the committee's attention on the very important issue of home health care for children.

As we all know the costs, both the financial and the emotional costs of hospital care and institutional care are astronomical. In many instances, as I am sure these witnesses will explain, these high costs can be greatly reduced.

I have long believed home health care is an option that would greatly benefit our citizens, both young and old, who need long-term health care. Home health care would reduce significantly both the financial and emotional costs of hospital care. I believe we must ensure that the barriers and obstacles placed in the paths of home health care are eliminated.

Many of Federal and State health care programs focus of inhospital care. I believe we must alter our focus from long-term hospital care as a solution to the problems of the chronically ill to home health care as a way to better meet the needs of the chronically ill. Currently, it is the exception rather than the rule for patients, especially children, to be directed to home health care agencies.

This policy, I believe, is inconsistent with our Nation's need to reduce the cost of health care; to find more personal, alternative forms of health care; and to address the individual needs of chronically ill children and older Americans.

I hope, Mr. Chairman, that this hearing will reveal the enormous value of home health care to the individuals who very much need these services. We also need to focus our attention and interest in providing quality care and reducing the high cost of our health care system. I hope after this hearing we will all agree upon the need to eliminate the barriers to providing quality home health care.

Senator PELL. And also I would like to congratulate Ms. Davis on her organization, the Visiting Nurses. I think, to my mind, of the various groups that I have seen and been exposed to in my State, at least, you do a better job of home care than any other and deserve a great deal more support than you are getting, and it would save the taxpayers a great deal of money if more reliance was placed on you and your expert abilities.

Ms. DAVIS. Thank you, Senator.

Senator NICKLES. Thank you, Senator Pell.

To all of our panelists, we do appreciate your input and expertise, and also the wonderful job that you are doing in helping children throughout the country. Thank you very much.

Our next panelists—we will kind of juggle the schedule to accommodate the schedule of Carolyne Davis, who is the Administrator of the Health Care Financing Administration, and also Dr. Vincent Hutchins, who is Division Director of Maternal and Children's Health, Health Resources and Services Administration.

Dr. Davis, I understand that you have a time constraint, and so we are trying to accommodate that. We do have one other panel as well.

I want to thank you both for coming today. It is always a pleasure to hear testimony from you and to work with you on legislative matters. You have proven that through effective Federal leadership, triumphs of social policy are fully achievable without concomitant increases in Federal bureaucracy.

Dr. Davis, I would particularly like to highlight a recent New York Times editorial which, without objection, I will insert into the hearing record.

[The following was received for the record:]

The New York Times

Founded in 1851

ADOLPH S. OCHS, *Publisher 1896-1935*
ARTHUR HAYS SULZBERGER, *Publisher 1935-1961*
ORVIL E. DRYFOOS, *Publisher 1961-1963*

ARTH...

...EDNESDAY, JUNE 12, 1985

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Health and Federal Leadership

Until very recently, the bankruptcy of Medicare was considered imminent. Now it has been avoided, at least for several years . . . Blue Cross is refunding premium money to the Federal employees and their employers . . . Hospitals compete for patients by offering fancy meals and amenities.

The run of health-related headlines masks still-larger news. Congress and the Reagan Administration have managed an apparently humane taming of hospital cost inflation. While caution may still be in order, so is credit for a triumph of social policy.

•

Until three years ago, even though general inflation was coming down, inflation of hospital costs had averaged 16 percent a year and hopes for relief seemed slight. Analysts ticked off the reasons: the aging of the population; the high cost of new medical technology; increasing tests and treatments per patient. The cost spiral threatened to bring bankruptcy to the trust fund financing hospital payments for Medicare, the $71 billion Federal program of medical insurance for the elderly. Some in the Administration favored harsh cuts in benefits, but Congress and the Health Care Finance Administration insisted on a regulatory reform to make hospitals more efficient.

Under Medicare rules then in force, hospitals could bill Washington for any reasonable charge, with few questions asked. The 1983 reform fixed reimbursements according to the illness being treated. If hospitals treated a patient for less than the typical cost, they could keep the difference — but had to absorb any overrun.

Some analysts predicted the new policy would fail because it applied only to Medicare. They feared that hospitals would simply pile additional bills on private insurers. What the critics failed to notice was that employers and the private insurers were also fed up with rising hospital costs. Employers who once considered better health benefits an easy way to settle a union contract began to recoil from the expense. They insisted on reviewing doctors' decisions to hospitalize and gave employees incentives to seek second opinions. They persuaded workers to pay larger insurance premiums and encouraged them to sign up for comprehensive care for a fixed fee. Doctors caught on fast and began performing in their offices procedures that once consumed days in the hospital.

The results have been dramatic. Before 1982, hospital admissions were going up 1.9 percent a year. Last year they declined 3.3 percent. The annual increase in hospital expenditures plummeted from 16.2 percent to 5.4 percent. The Medicare Trust fund escaped imminent bankruptcy as the rate of increase in hospital payouts dropped by nearly half. Some private health insurance premiums have actually been reduced.

Has the public's health been endangered? Remarkably, no one has been able to demonstrate any dramatic decline in quality of hospital care. Problems are looming for hospitals that serve many poor people, since the Feds have so far refused them more generous allowances ordered by Congress. And continued vigilance is needed to insure that more cost-cutting doesn't endanger patients in more affluent communities. But the big news remains big indeed. America has profoundly improved the efficiency of medical care delivery.

This achievement required the determination of Congressional and Administration planners cooperating with private employers and insurers. With social activism on the wane, this victory confirms a point too easily forgotten: intelligent Federal leadership makes a powerful difference.

Senator NICKLES. The editorial, entitled "Health and Federal Leadership," praises the Reagan administration for its efforts to tame health care cost inflation, for its implementation of the prospective payment system, and for its work with employers and private insurers.

The result, according to the New York Times, is "big news * * * America has profoundly improved the efficiency of medical care delivery." The credit certainly belongs to President Reagan and Ms. Heckler, but to an enormous extent it belongs to the tireless efforts of Dr. Davis.

So, Dr. Davis, I am particularly grateful that you have changed your travel plans so you could be with us today and we welcome your comments.

STATEMENT OF CAROLYNE K. DAVIS, ADMINISTRATOR, HEALTH CARE FINANCING ADMINISTRATION, ACCOMPANIED BY ROBERT WREN, DIRECTOR, OFFICE OF COVERAGE POLICY; AND VINCENT L. HUTCHINS, DIRECTOR, DIVISION OF MATERNAL AND CHILD HEALTH, HEALTH RESOURCES AND SERVICES ADMINISTRATION, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY MERLE McPHERSON, DIVISION OF MATERNAL AND CHILD HEALTH, BUREAU OF HEALTH CARE DELIVERY AND ASSISTANCE

Dr. DAVIS. Thank you very much, Senator Nickles.

First of all, I would like to apologize to Katie Beckett because I am going in front of Katie and Katie has been very patient all morning here, so we will try to be very brief.

Senator NICKLES. Thank you.

Dr. DAVIS. Mr. Chairman, I am very pleased, however, to be here to discuss home and community-based care under the Medicaid Program, primarily the part that is focusing on the assistance that we have been able to offer to the chronically ill children.

I am accompanied on my right by Mr. Robert Wren, who is the Director of the Health Care Financing Administration's Office of Coverage Policy.

As you well know, until recently there has been little flexibility in the Medicaid rules for States to provide the noninstitutional types of long-term care services, particularly if they are nonmedical services, that are needed in order to maintain a disabled person at home.

Furthermore, the Social Security income eligibility rules further restricted the States from providing those kinds of Medicaid services outside of an institution. All of us, of course, well remember November 1981 when President Reagan in a press conference spoke of Katie Beckett from Cedar Rapids, IA, who was at that point respirator-dependent and had to remain inside an institution in order to retain her Medicaid eligibility.

Needless to say, we immediately began to look at that particular issue, and as a result of that we did develop a waiver policy for the SSI deeming requirement An intradepartmental board was established in early 1982 to review similar cases that would be submitted by the States on an individual basis, and to look, then, at how we could apply the new SSI deeming rule to those cases.

The new deeming requirements now allow that individuals who were institutionalized can be treated at home for less cost and yet maintain their Medicaid eligibility.

Now, the board was created on a temporary basis to make case-by-case decisions based on the State's documentation of the anticipated savings to Medicaid and an assurance, also, that there would be a continued high-quality medical care provided in the home.

Another approach that has been developed was through what we refer to as the section 2176 program that the Congress passed in the Omnibus Reconciliation Act, which authorized further development of a home and community-based waiver program.

Under that program, the Secretary can waive certain Medicaid requirements and allow the States to provide cost-effective Medicaid coverage in a very broad array of home and community-type services which the individual may need in order to avoid institutionalization.

Within section 2176, there is a provision, also, to allow the States to cover individuals at home who, like Katie Beckett, would normally have qualified only when they were in an institution.

Then in 1982, with the Tax Equity and Fiscal Responsibility Act, States were allowed to waive their deeming requirements for the disabled children under 18 who could be cared for in a less costly home environment.

So, with those new options available to the States, we thought that the tenure of the review board would need to be extended only through December 31, 1984, except for requests that were pending at that time at the end of December 1984.

As of June of 1985, the board had approved 180 individual cases and disapproved none, and there are still some pending. To assist the States, however, in using their section 2176 waiver process, we in the Department established a very streamlined procedure in which the States may request what is known as a model waiver. That is either in addition to or in lieu of the larger home and community-based waiver program.

The model waiver, of course, is limited to 50 cases of blind or disabled children or adults who would otherwise be eligible for Medicaid only when they were institutionalized. The States must offer, however, at least one home and community-based service, and primarily they offer case management, which we have heard spoken about today as to how important it is. And then they also must make available all the other services that are included within their State plan.

To encourage the States to participate in the model waiver program, we have sent instructions to our State Medicaid agencies on exactly how that waiver process works. In fact, the model waiver application is almost a fill-in-the-blank form at this point.

We have held workshops at each and every one of our State Medicaid directors' conferences on the model waivers. And, in addition, both former Secretary Schweiker and Secretary Heckler have reminded the Governors several times now of the availability of the waivers and have urged them to pursue the waiver option.

Earlier in today's testimony we saw and heard some heart wrenching examples of families with technology-dependent chil-

dren who look forward to a time when they can live more independent from their specific disability and the hospital.

I want to divert from my testimony 1 minute to mention something very positive that Secretary Heckler is doing for technology dependent people. She is in the process of establishing the "National Initiative on Technology and the Disabled." This initiative was inspired by President Reagan's establishment of the "Decade of the Disabled" in 1982. With the cosponsorship of the Department of Defense, NASA and other Federal agencies Secretary Heckler, Secretary Casper Weinberger and Administrator James Beggs are inlisting the support of the aerospace and defense industries to lend their technological inventiveness and engineering prowess to find new ways to help the 41 million people in our country with disabilities gain more hope and freedom. For those who are interested I have more information with me and will be happy to share it with you. The Department of Health and Human Services is with Secretary Heckler's leadership continuing to look for new and better ways and alternatives to help people with disablities like the kind we see here today.

Our staff in HCFA work with the States to assist them in developing those waiver proposals, too. Most recently in May, I was pleased to approve a model waiver for chronically ill children in the State of Minnesota, and that program was able to go into operation immediately due in large part to the fact that the staff worked with the State people for over 50 days in order to have an acceptable waiver application.

As of this date, Minnesota has only one institutionalized child at home and three others are awaiting certain kinds of electrical modifications to their homes so that they can be returned there, and those costs will also, in terms of the alterations, be borne under the waiver program.

Once a waiver is granted, it is effective for 3 years and then the States with an approved model waiver can renew it, upon request, for an additional 3-year period of time, subject, of course, to our determination that they have met all the statutory requirements.

As of May 31, we have had a total of 30 model waiver requests that have been received from some 19 States, and those model waivers are targeted to the severely disabled children who do live at home with their parents in the majority of cases.

A few States have specifically used the model waiver to permit children who are currently living in the institutions to return home without the loss of their Medicaid eligibility program.

Four of the programs cover case management services only. In those particular cases, I think that the model waiver is primarily used as a way to target the group with the access to the normal range of services inside the States Medicaid Program.

The remaining 14 in the model waiver program provide a variety of home and community-based services, in addition to the normal Medicaid services, and those kinds of extensive benefit packages seem to reflect the severity of disability of the persons that are being targeted in the particular model waiver program. And it indicates, too, I think, the high level of supportive care that is sometimes required to keep those individuals at home.

Then there are an additional 14 States that have larger, what we call regular, section 2176 waivers which also cover the Katie Beckett-type cases and which involve an institutional deeming process.

So for all of the waivers, including the model waiver, I think that the major issue in terms of approvability has been the issue of cost-effectiveness and the issue of guarantee of quality of care.

We have been interested, in our Office of Demonstration and Evaluation, in doing a very thorough evaluation of the impact on the program and our evaluation program, begun in late 1983, is scheduled to be completed in September of 1986.

But as I sat here today and looked at the evidence of the people who have been helped already by the various program efforts, Mr. Chairman, it is very clear that the flexibility that the Federal Government has been able to provide in the various States has indeed been welcomed and put to good use, and for that I am quite grateful.

But I am also hopeful that we will be able to improve upon what we have accomplished to date so that more of the chronically ill children can remain at home rather than be separated from their families and cared for in an institution.

I would be happy to answer any questions.

[The prepared statement of Dr. Davis and questions submitted by Senator Pell with responses follow:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Washington, D.C. 20201

STATEMENT OF

CAROLYNE K. DAVIS, PH.D.

ADMINISTRATOR

HEALTH CARE FINANCING ADMINISTRATION

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

JUNE 18, 1985

MR CHAIRMAN, I AM PLEASED TO BE HERE TODAY TO DISCUSS HOME AND COMMUNITY-BASED CARE UNDER MEDICAID, FOCUSING PARTICULARLY ON THE ASSISTANCE WE HAVE BEEN ABLE TO OFFER CHRONICALLY ILL CHILDREN THROUGH THE SEVERAL OPTIONS THAT ARE AVAILABLE TO THE STATES. I AM ACCOMPANIED BY ROBERT WREN, DIRECTOR OF THE HEALTH CARE FINANCING ADMINISTRATION'S (HCFA) OFFICE OF COVERAGE POLICY IN THE BUREAU OF ELIGIBILITY, REIMBURSEMENT AND COVERAGE.

BACKGROUND

AS YOU KNOW, PAYMENTS FOR INSTITUTIONAL LONG-TERM CARE SERVICES UNDER MEDICAID ACCOUNT FOR AN INCREASINGLY LARGER SHARE OF THE MEDICAID BUDGET. IN 1983, PAYMENTS OF ALMOST $14 BILLION IN FEDERAL AND STATE FUNDS REPRESENTED 43 PERCENT OF ALL PROGRAM COSTS. BY 1990, THESE PAYMENTS CAN BE EXPECTED TO DOUBLE, IF CURRENT UTILIZATION TRENDS CONTINUE.

UNTIL RECENTLY THERE WAS LITTLE FLEXIBILITY UNDER MEDICAID RULES FOR STATES TO PROVIDE NON-INSTITUTIONAL LONG-TERM CARE SERVICES, PARTICULARLY NON-MEDICAL SERVICES NEEDED TO MAINTAIN DISABLED PERSONS AT HOME. ELIGIBILITY RULES FURTHER RESTRICTED STATES FROM PROVIDING MEDICAID SERVICES OUTSIDE OF AN INSTITUTION.

THIS PARTICULAR PROBLEM WAS EMPHASIZED WHEN IN A NOVEMBER 1981 PRESS CONFERENCE PRESIDENT REAGAN SPOKE OF A LITTLE GIRL, KATIE BECKETT FROM CEDAR RAPIDS, IOWA, WHO WAS RESPIRATOR-DEPENDENT AND HAD TO REMAIN IN AN INSTITUTION IN ORDER TO RETAIN THE MEDICAID ELIGIBILITY THAT PAID FOR HER CARE. KATIE BECKETT QUALIFIED FOR

MEDICAID BECAUSE HER PARENTS' INCOME WAS NOT DEEMED AVAILABLE TO HER IN AN INSTITUTIONAL SETTING. HOWEVER, SHE WAS READY TO GO HOME ACCORDING TO HER PHYSICIAN; HER PARENTS NATURALLY WANTED HER AT HOME; AND THE COST OF TREATMENT AT HOME WOULD BE SUBSTANTIALLY LESS THAN IT WAS IN THE HOSPITAL. BUT ONCE SHE LEFT AN INSTITUTIONAL SETTING AND RETURNED TO LIVE WITH HER FAMILY, THE FAMILY'S INCOME AND RESOURCES WOULD MAKE HER INELIGIBLE FOR MEDICAID, WHICH WAS THE ONLY MEANS BY WHICH THE FAMILY COULD AFFORD HER CARE.

AS A RESULT, THE DEPARTMENT OF HEALTH AND HUMAN SERVICES IN EARLY 1982 ESTABLISHED AN INTRA-DEPARTMENT BOARD, TO REVIEW SIMILAR CASES SUBMITTED BY STATE MEDICAID AGENCIES AND TO APPLY NEW SSI DEEMING RULES TO THOSE CASES. THESE NEW DEEMING REQUIREMENTS WERE AIMED AT ALLOWING INDIVIDUALS WHO WERE INSTITUTIONALIZED TO BE TREATED AT HOME FOR LESS COST AND TO RETAIN THEIR MEDICAID ELIGIBILITY. THE BOARD WAS CREATED ON A TEMPORARY BASIS AND WAS TO MAKE CASE-BY-CASE DECISIONS BASED UPON A STATE'S DOCUMENTATION OF ANTICIPATED SAVINGS TO THE MEDICAID PROGRAM AND AN ASSURANCE OF CONTINUED HIGH QUALITY MEDICAL CARE FOR A DEINSTITUTIONALIZED PATIENT.

STATE OPTIONS FOR HOME-BASED LONG TERM CARE

AS ANOTHER APPROACH TO THE PROBLEM OF MEDICAID'S EMPHASIS UPON INSTITUTIONAL CARE, CONGRESS IN SECTION 2176 OF THE OMNIBUS BUDGET RECONCILIATION ACT OF 1981, P.L. 97-35, AUTHORIZED THE

HOME AND COMMUNITY-BASED AND MODEL WAIVER PROGRAM. IT AUTHORIZED THE SECRETARY TO WAIVE CERTAIN MEDICAID REQUIREMENTS TO ALLOW STATES TO PROVIDE MEDICAID COVERAGE OF A BROAD ARRAY OF HOME AND COMMUNITY-BASED SERVICES OTHER THAN ROOM AND BOARD WHICH AN INDIVIDUAL MAY NEED TO AVOID INSTITUTIONALIZATION OR TO BE DEINSTITUTIONALIZED. SECTION 2176 ALSO CONTAINED PROVISIONS WHICH ALLOWED STATES TO COVER PEOPLE AT HOME WHO, LIKE KATIE BECKETT, WOULD NORMALLY HAVE QUALIFIED ONLY IF IN AN INSTITUTION.

THEN, IN 1982 WITH THE ENACTMENT OF THE TAX EQUITY AND FISCAL RESPONSIBILITY ACT, P.L. 97-248, STATES WERE ALLOWED, AT THEIR OPTION, TO WAIVE DEEMING REQUIREMENTS FOR DISABLED CHILDREN UNDER 18 WHO COULD BE CARED FOR AT LESS COST AT HOME THAN IN AN INSTITUTION.

WITH THESE NEW OPTIONS AVAILABLE TO THE STATES, THE TENURE OF THE REVIEW BOARD WAS EXTENDED ONLY THROUGH DECEMBER 31, 1984, EXCEPT FOR REQUESTS PENDING BEFORE THE BOARD AT THAT TIME. AS OF JUNE 7, 1985, THE BOARD HAD APPROVED 180 CASES AND DISAPPROVED NONE. DURING ITS EXISTENCE WE HAD THE OPPORTUNITY TO WORK WITH INDIVIDUAL STATES TO DEVELOP AN APPROPRIATE HOME AND COMMUNITY-BASED OR MODEL WAIVER ALTERNATIVE.

IN ORDER TO ENCOURAGE GREATER STATE PARTICIPATION WE ALSO SENT INTRUCTIONS TO STATE MEDICAID AGENCIES ON HOW THE WAIVER PROCESS WORKED. WE HELD WORKSHOPS ON MODEL WAIVERS AT OUR STATE MEDICAID

DIRECTORS' MEETING. IN ADDITION, BOTH FORMER SECRETARY SCHWEIKER AND SECRETARY HECKLER REMINDED THE GOVERNORS OF EACH STATE SEVERAL TIMES OF THE AVAILABILITY OF WAIVERS AND URGED THEM TO PURSUE THE WAIVER OPTIONS SO THAT STATE PROGRAMS COULD BE IN PLACE BEFORE THE TERM OF THE FEDERAL BOARD EXPIRED.

SECTION 2176

TO ASSIST STATES IN USING THE SECTION 2176 WAIVER PROCESS TO AVOID UNNECESSARY INSTITUTIONALIZATION, THE DEPARTMENT ESTABLISHED A STREAMLINED PROCEDURE UNDER WHICH STATES MAY REQUEST WHAT IS KNOWN AS A "MODEL WAIVER", IN ADDITION TO OR IN LIEU OF A FULLER HOME AND COMMUNITY-BASED WAIVER. COVERAGE UNDER A MODEL WAIVER IS LIMITED TO 50 CASES OF BLIND OR DISABLED CHILDREN AND ADULTS WHO WOULD OTHERWISE BE ELIGIBLE FOR MEDICAID ONLY IF INSTITUTIONALIZED.

ELIGIBILITY IN MODEL WAIVER PROGRAMS IS NOT RESTRICTED TO JUST THESE GROUPS. PERSONS WHO ALREADY MEET MEDICAID ELIGIBILITY CRITERIA OUTSIDE OF AN INSTITUTION CAN ALSO RECEIVE HOME AND COMMUNITY-BASED CARE IN MODEL WAIVER PROGRAMS. HOWEVER, ELIGIBILITY IN MODEL WAIVER PROGRAMS IS RESTRICTED TO PERSONS WHO MEET MEDICAID CATEGORICAL CRITERIA FOR BLINDNESS OR DISABILITY; AGED INDIVIDUALS ARE NOT ELIGIBLE UNLESS THEY ALSO QUALIFY AS BLIND OR DISABLED.

UNDER A MODEL WAIVER REQUEST, STATES MUST OFFER AT LEAST ONE HOME AND COMMUNITY-BASED SERVICE, SUCH AS CASE MANAGEMENT, AND MAKE AVAILABLE THOSE SERVICES NOW INCLUDED IN THE STATE PLAN. STATES WITH APPROVED MODEL WAIVERS MUST ASSURE THE SATISFACTION OF ALL THE OTHER STATUTORY AND REGULATORY REQUIREMENTS OF SECTION 2176.

SECTION 2176 WAIVER REQUIREMENTS

TO BE GRANTED A MORE BROADLY BASED HOME AND COMMUNITY-BASED WAIVER OR A LIMITED MODEL WAIVER, STATES MUST MEET CERTAIN REQUIREMENTS INCLUDING:

- NECESSARY SAFEGUARDS HAVE BEEN TAKEN TO PROTECT THE HEALTH AND WELFARE OF BENEFICIARIES, INCLUDING ADEQUATE STANDARDS FOR ALL TYPES OF PROVIDERS OF SERVICES UNDER THE WAIVER.

- THERE WILL BE FINANCIAL ACCOUNTABILITY FOR FUNDS SPENT UNDER THE WAIVER, AND THE STATE WILL PROVIDE FOR AN INDEPENDENT AUDIT OF ITS WAIVER EXPENDITURES IN MOST CASES AS WELL AS AN INDEPENDENT ASSESSMENT OF EACH WAIVER PROGRAM THAT EVALUATES THE QUALITY OF CARE PROVIDED, ACCESS TO CARE, AND COST EFFECTIVENESS;

- THE STATE WILL PROVIDE FOR AN EVALUATION (AND PERIODIC REEVALUATIONS) OF THE NEED FOR THE INPATIENT SERVICES FOR INDIVIDUALS WHO ARE ENTITLED TO AND REQUIRE THE LEVEL OF CARE PROVIDED IN A SNF OR ICF;

- Individuals likely to require SNF or ICF level of care are informed of feasible alternatives available under the waiver and are given the choice of institutional or non-institutional services;

- The State will provide on an annual basis information on the impact of the waiver.

- States, as part of their waiver requests, estimate total Medicaid costs, for acute as well as long-term care under the waiver versus without the waiver and assure that total Medicaid costs will not increase as a result of granting the waiver.

- The agency's actual total expenditures for home and community-based services provided to waiver recipients will not for any waiver year exceed the amount that would have been incurred by Medicaid absent the waiver.

- All facilities covered by Section 1616(e) of the Act (i.e., the Keys amendment regarding board and care facilities) in which waiver services are provided are in compliance with State standards established pursuant to that section.

- Assurance of compliance with a data collection plan designed HHS on the impact and cost of the waiver.

HCFA WORKS WITH THE STATES TO ASSIST THEM IN DEVELOPING THEIR WAIVER PROPOSALS. FOR EXAMPLE, I WAS PLEASED TO APPROVE ON MAY 13 A MODEL WAIVER FOR CHRONICALLY ILL CHILDREN IN THE STATE OF MINNESOTA. THE PROGRAM WAS ABLE TO GO INTO OPERATION IMMEDIATELY AND WAS ACTUALLY EFFECTIVE APRIL 1. THIS WAS DUE IN LARGE PART TO THE FACT THAT MY STAFF WORKED WITH THE STATE FOR OVER 50 DAYS IN ORDER TO HAVE AN ACCEPTABLE WAIVER APPLICATION. AS OF THIS DATE, MINNESOTA HAS ONE FORMERLY INSTITUTIONALIZED CHILD AT HOME, AND THREE OTHERS WAITING FOR CERTAIN ELECTRICAL MODIFICATIONS TO BE MADE IN THEIR HOMES BEFORE THEY CAN RETURN THERE. MOST OF THE COST OF THESE ALTERATIONS WILL BE BORNE BY THE WAIVER PROGRAM.

THE ACTUAL PROCESS WE FOLLOW PROVIDES THAT WAIVER REQUESTS ARE DEEMED APPROVED UNLESS THE DEPARTMENT, THROUGH HCFA, DISAPPROVES OR REQUESTS ADDITIONAL INFORMATION WITHIN 90 DAYS OF RECEIPT. ONCE GRANTED, WAIVERS ARE EFFECTIVE FOR THREE YEARS. UNDER THE STATUTE STATES MUST FILE ANNUAL REPORTS ON THEIR WAIVER PROGRAM RECIPIENTS AND EXPENDITURES WHICH ARE USED FOR PROGRAM MONITORING PURPOSES. ANNUAL OVERSIGHT REVIEWS OF APPROVED WAIVERS ARE ALSO CONDUCTED AS PART OF THE MEDICAID STATE ASSESSMENT REVIEW PROCESS. WAIVERS ARE MONITORED JOINTLY BY HCFA CENTRAL AND REGIONAL OFFICES.

WAIVERS MAY BE RENEWED, UPON REQUEST, FOR AN ADDITIONAL THREE-YEAR PERIOD, SUBJECT TO A SECRETARIAL DETERMINATION THAT FOR THE PREVIOUS THREE-YEAR PERIOD, THE STATE MET THE NECESSARY STATUTORY REQUIREMENTS.

STATUS OF MODEL WAIVER PROGRAM

- AS OF MAY 31, 1985, A TOTAL OF 30 MODEL WAIVER REQUESTS HAD BEEN RECEIVED FROM 19 STATES.

- THE MAJORITY OF MODEL WAIVERS ARE TARGETED TO SEVERELY DISABLED CHILDREN LIVING AT HOME WITH THEIR PARENTS. A FEW STATES ARE SPECIFICALLY USING MODEL WAIVERS TO PERMIT CHILDREN CURRENTLY LIVING IN INSTITUTIONS TO RETURN HOME WITHOUT LOSS OF MEDICAID ELIGIBILITY.

- FOUR PROGRAMS PROVIDE COVERAGE FOR CASE MAMANGEMENT SERVICES ONLY. IN THESE STATES, THE MODEL WAIVER IS PRIMARILY BEING USED AS A WAY TO PROVIDE THE TARGET GROUP WITH ACCESS TO THE USUAL RANGE OF SERVICES IN THE STATE'S MEDICAID PLAN.

- THE REMAINING FOURTEEN ACTIVE MODEL WAIVER PROGRAMS PROVIDE A WIDE ARRAY OF HOME AND COMMUNITY-BASED SERVICES IN ADDITION TO THE USUAL MEDICAID SERVICES. THIS EXTENSIVE BENEFIT PACKAGE REFLECTS THE SEVERE

DISABILITY OF PERSONS BEING TARGETED IN MODEL WAIVER PROGRAMS AND THE HIGH LEVEL OF SUPPORTIVE CARE REQUIRED TO KEEP THEM AT HOME. ANOTHER 8 STATES HAVE LARGER NON-MODEL WAIVERS UNDER SECTION 2176 WHICH COVER KATIE BECKETT-TYPE CASES (I.E., INSTITUTIONAL DEEMING) UNDER A PROGRAM OF HOME AND COMMUNITY-BASED CARE.

WAIVER PROGRAM EVALUATION

FOR ALL WAIVERS, INCLUDING THE MODEL WAIVERS, THE ISSUE OF COST EFFECTIVENESS IS OF GREAT CONCERN. COST INCREASES CAN OCCUR UNLESS WAIVER SERVICES ARE CAREFULLY TARGETED, THE SUPPLY OF LONG-TERM CARE BEDS IS CONTROLLED, AND FUTURE TRENDS IN NURSING HOME UTILIZATION AND EXPENDITURES ARE ACCURATELY PREDICTED. THIS IS ONE OF THE AREAS THAT OUR OFFICE OF DEMONSTRATIONS AND EVALUATION IS STUDYING IN A THOROUGH INDEPENDENT EVALUATION OF THE IMPACT OF THE SECTION 2176 WAIVER PROGRAM. THE EVALUATION STUDY WAS BEGUN IN LATE 1983 AND IS SCHEDULED TO RUN THROUGH SEPTEMBER 1986.

CONCLUSION

AS I SIT HERE TODAY AND SEE EVIDENCE OF THE PEOPLE WHO HAVE BEEN HELPED BY OUR EFFORTS, IT IS CLEAR THAT THE FLEXIBILITY GIVEN THE STATES HAS BEEN WELCOMED AND PUT TO USE. FOR THAT, I AM VERY GRATEFUL. I AM HOPEFUL THAT WE WILL BE ABLE TO IMPROVE UPON WHAT WE HAVE ACCOMPLISHED SO FAR SO THAT MORE OF OUR CHRONICALLY ILL CHILDREN MAY REMAIN AT HOME RATHER THAN BEING SEPARATED FROM THEIR FAMILIES AND CARED FOR IN INSTITUTIONS.

I WILL BE HAPPY TO RESPOND TO ANY QUESTIONS YOU MAY HAVE.

QUESTIONS FOR CAROLYN K. DAVIS FROM SENATOR PELL

I.Q. From your testimony on 18 June 1985 before the Labor and Human Resources Committee, it appears that a State, to obtain a more broadly based home and community-based health care waiver or even a limited model waiver, must meet a great number of specific requirements. Do you not believe that these complex regulatory requirements discourage a State from expanding its health care coverage to include home health care? Could you explain the purpose behind these regulatory requirements?

A. In order to receive a Medicaid home and community-based (HCB) waiver, the statute requires that the States provide specific statutory assurances satisfactory to the Secretary. These include assurances regarding safeguards that have been taken to protect the health and welfare of beneficiaries; requirements to comply with a data collection plan; informing beneficiaries of choice; an assessment of need for level of care; and requirements for financial accountability for funds spent under the waiver. In addition, the States must assure that, for a given fiscal year, expenditures for Medicaid services provided to individuals under the program do not exceed either on an average per capita or aggregate basis amounts the State reasonably estimates would have been expended for medical assistance to these individuals absent the waiver. A formula for the provision of this assurance is provided in regulations.

To implement these requirements, the program issued interim final regulations in late 1981. Our final regulations, issued in March of this year, are based in large measure on our initial experiences in working intensively with the States to enable them to develop waiver programs approvable under the statute. They include some significant changes in requirements, procedures, and documentation designed to help us improve our oversight role, thus, maximizing the likelihood that statutorily required assurances aimed at preventing program cost increases and assuring the health and safety of beneficiaries will be met.

These new waiver program requirements are not meant to harm the program, impede its operations, or discourage States from participating. They are required to avoid significant unexpected increases in program dollars, and potential problems related to quality of care. These requirements help insure that aggregate Medicaid costs will not increase while enabling frail and disabled beneficiaries to remain at home and receive needed services.

States requesting limited "model waivers" may still use an abbreviated set of pre-printed forms through which review of their request is expedited. These forms are being revised to reflect the new regulatory requirements.

While some States have expressed concern about the new rules, there is no evidence at all to indicate that the remarkable enthusiasm States have shown for the waiver program since its inception has diminished in any way. Forty-six States are currently operating 104 separate regular and model waiver programs. An additional 29 applications are under review. Since publication of the new regulations on March 13, the Health Care Financing Administration (HCFA) has continued to receive requests for new waivers as well as requests for renewals of currently operating programs. In addition, on May 1, HCFA advised all States of the additional assurances and information required for all approved waiver programs. As of July 5, 1985, we had received State responses on 54 existing approved waivers. This immediate response clearly indicates that the new regulations have not caused a decline in State interest in participating in the waiver program.

2.Q. During the 18 June 1985 hearing, a number of the witnesses, specifically those who provide home health care, testified that there were a number of disincentives to home health care. One of those disincentives lies with your agency. That disincentive is your agency's failure to alter its focus on in-hospital care. Generally, that focus has been to provide immediate reimbursement for in-hospital care but to thwart the process of reimbursing home health care services or to provide different levels of services to children with disabilities who are living with their parents. Could you please explain why your agency has failed to encourage home health care by providing the same level of services for disabled children living at home with their parents, or by providing the same level of services for home health care providers and recipients?

A. The Health Care Financing Administration administers two distinct programs authorized under the Social Security Act -- Medicare (Title XVIII) and Medicaid (under Title XIX). Medicare is a Federally-administered hospital and medical insurance program covering hospital, physician, and other medical services for persons aged 65 or over, disabled persons who cannot engage in gainful employment, and most persons with end-stage renal disease. Medicaid is a State-administered Federally-matched medical assistance program providing services for certain low-income individuals and families who, in general gain eligibility for Medicaid because they are receiving cash welfare payments under either the Aid to Families with Dependent Children (AFDC) program or the Supplemental Security (SSI) program for aged, blind or disabled individuals.

While both Medicare and Medicaid offer home health care benefits, they are not comparable and should not be confused. Medicare's extended care benefits, for skilled nursing facility level of care and home health agency services, were designed as short-term post-acute care benefits. This is not true of Medicaid, which has become the single most significant source of public funding for the costly medical and long-term care needs of chronically ill, disabled children and adults living both inside and outside of institutions providing all level of skilled and intermediate care.

As indicated elsewhere in these responses to your questions, HCFA can and is taking steps to insure greater uniformity in intermediary decisions affecting home health coverage and reimbursement for Medicare beneficiaries. This same uniformity, however, cannot be mandated for the Title XIX Medicaid program, under which each State administers its own program within broad Federal requirements and guidelines. These requirements allow States considerable discretion in determining income and other resource criteria for eligibility, covered benefits, and provider payment mechanisms. As a result, although each State is required to provide certain basic services to all its Medicaid recipients, the characteristics of Medicaid programs vary considerably from State to State.

That HCFA cannot, by law, mandate uniformity of Medicaid home health coverage does not in any way mean that we have not acted to encourage the States to develop programs which permit families who wish to care for their disabled children at home to do so under certain circumstances

with Medicaid assistance. In fact, the general availability of home health services under Medicaid is not at issue in cases similar to those highlighted in the June 18th hearing, because all States must offer home health services (as defined in Medicaid regulations at 42 CFR 440.70) to all Medicaid recipients who are entitled to skilled nursing services under their State plans and almost every State makes SNF services available to disabled children.

The issues raised for Medicaid by these cases are twofold. The first involves a question of basic Medicaid eligibility for persons with family incomes too high to qualify outside of an institution for SSI payments, on which Medicaid eligibility for the disabled is normally based. The second involves the fact that providing for the long-term care needs of disabled or frail elderly persons in home settings often requires the provision of personal care and support services that are not strictly medical in nature, and which are, therefore, not generally covered by any private or public health insurance program, including Medicaid.

My testimony outlined the multiple options which have been made available to States since 1981 to provide individualized long-term care services at home under Medicaid to chronically ill children and adults. These include establishment of our interim intra-Departmental board to provide case-by-case waivers of deeming requirements, enactment of the Section 2176 waiver program, development of the streamlined "model waiver" to facilitate approval of limited waivers involving institutional deeming for disabled children and adults, and enactment of Section 134 of TEFRA which permits States the option of waiving SSI deeming requirements to provide Medicaid at home for children under 18 who would otherwise be eligible only if institutionalized.

We have encouraged State participation in the Section 2176 waiver program in a number of ways. First, HCFA published interim rules for the program within only 60 days after its enactment to expedite its implementation. Further, we published a set of forms for States wishing to apply for 2176 "model waivers." These forms were designed so that States could basically "fill in the blanks" and HCFA could promptly process the waiver requests. We have also made the waiver program a topic at all of our Medicaid Directors Conferences since 1982, and encouraged participation by States through letters from both former Secretary Schweicker and Secretary Heckler.

Substantial staff time in HCFA has been allocated to the waiver program. In fact, we believe that many waiver requests would not have qualified technically without the time and expertise devoted by HCFA staff to both waiver applications and renewals.

At this time, only 16 States still do not have programs in place which waive SSI institutional deeming rules to address the long-term home care needs of chronically ill disabled children. These States have not applied for a regular or model home and community-based waiver for this group, nor have they adopted a Section 134 amendment to their State plans. We expect that some of these States, which have made use of the intra-Departmental board, will begin to apply for model waivers now that the board's tenure is expiring.

The popularity of the waiver program with the States so far, is convincing evidence that the proper incentives for State participation appear to be already largely in place. In the absence of solid evaluation data, we would be very reluctuant to recommend any significant program changes at this time that would jeopardize the opportunities for flexibility which the program now affords the States.

3.Q. I understand from your testimony that your agency has worked with a number of States to expand their options in the home health care arena. Could you explain what your future plans are to encourage the utilization of home health care, generally, and could you outline, specifically, what future actions you will be taking concerning increasing State participation?

A. The Department continues to make vigorous efforts to encourage Medicaid home and community-based waiver use. States may receive technical assistance from HCFA at any stage of the waiver submission and review process. The initiative for any waiver request, however, must come from the State, which we believe is in a better position to judge the appropriateness of community versus institutional placement for the Medicaid clients it serves.

At this time, we believe that the best way to encourage States to move more Medicaid clients out of long-term care institutions into community-based care is to continue to offer them the opportunity that the waiver program now provides and to give them sufficient time to see some solid results from their own and other States' initial waiver efforts. We expect that our own ongoing waiver program evaluation, which will be completed in 1986, may help to pinpoint more specific ways to aid States which choose to emphasize deinstitutionalization under their waiver programs.

We are also, through our demonstration authority, conducting a number of home health and community-based care projects that cover a myriad of such services for a wide spectrum of Medicare and Medicaid beneficiaries. As a further demonstration of our interest in home health care, we are participating with the Department in the National Channeling Demonstration which is designed to determine whether the long-term needs of the elderly impaired can be met in a cost-effective way through a community-based system of case assessment, care planning, and care management.

We believe that these types of projects, along with the waiver program evaluation, will help us to address more specific recommendations for increased State participation.

4.Q. Have the administrative costs associated with Medicare and Medicaid increased or decreased with the expansion of Federal reimbursement to home health care providers? If administrative costs have increased, could you please explain the reason for the increase?

A. HCFA does not collect administrative cost data for either the Medicaid or Medicare programs by type of provider. Therefore, it is not possible to associate administrative cost fluctuations in either program with increased program expenditures for services provided by a single category of provider (in this case, home health agencies).

Overall, rates of increase in administrative costs for both the Medicare and Medicaid programs have remained relatively stable since 1981, reflecting only expected inflationary increases for each program.

5.Q. As I understand, one of the very real problems confronting home health care providers is their financial insecurity. As I understand further, this financial insecurity is, in large part, caused by your agency's failure to establish clear and meaningful reimbursement guidelines. Individuals who provide home health care to both chronically-ill children and adults cannot rely on your agency or the local fiscal intermediary to grant or deny reimbursement in a consistent manner. Will your agency be addressing this matter in the near future? And, will these guidelines be applicable to both Medicare and Medicaid cases?

A. The Congress, in the Deficit Reduction Act, instructed HCFA to reduce the number of Medicare home health intermediaries to no more than ten. This should encourage more uniform coverage and reimbursement decisions. We have already published a draft notice announcing tentatively the ten intermediaries selected. We intend to finalize the notice in the fall and begin moving freestanding home health agencies to their new intermediary at the end of this fiscal year.

In addition to the reduction in the number of Medicare intermediaries for freestanding home health agencies, HCFA is instituting a new reporting form to assist in coverage decisions. This new form, to be completed by home health agencies, will provide better information for our intermediaries to make uniform coverage decisions. We should begin utilizing this form in September 1985.

In regard to your question about uniform guidelines for Medicare and Medicaid, it is important to remember that Medicaid is a State-administered program. Although HCFA approves State plan amendments and waiver requests, we are not involved in establishing reimbursement and coverage instructions used by the States to pay individual bills. Thus, across a number of States, coverage and reimbursement guidelines may differ radically. However, because of the State-specific nature of the Medicaid program, more consistent guidelines cannot be mandated.

6.Q. What are your agency's specific plans to assist in reducing the cost of health care for chronically ill children and adults?

A. HCFA intends to continue efforts to encourage States to avail themselves of the home and community-based waiver program. We believe that this program has the potential for reducing the cost of health care for those individuals who otherwise would have been institutionalized.

However, our comprehensive evaluation of the HCB program will not be completed until 1986. Because of that fact and because of our 10-year experience with related demonstrations showing the difficulties with predicting cost-effective home care service structures, we feel that it is premature to recommend specific strategies for reducing Medicaid costs in this area. We expect that this thorough evaluation will produce the kind of careful analysis needed to suggest specific recommendations for reducing costs while maintaining appropriate and, quality alternative services.

Senator NICKLES. Thank you, Dr. Davis.

Senator HATCH.

The CHAIRMAN. Well, Dr. Davis, thank you for being here. I just have a couple of questions. Based on your experience with the model waivers, what are really the most common reasons why States do not qualify for such waivers?

Dr. DAVIS. I think the major problem as we have worked with the States has been to get them to be able to make a correct estimate of the expenditures that would be used within the model waiver. That has been primarily the activity where the State people and my staff have engaged in day-to-day conversations as we have moved through the process.

The CHAIRMAN. I see. Now, I am anxious to implement changes in national policy with regard to home care to make it available to all chronically ill children, and I understand that it is your position that it is essential in order to do so that we provide that it saves money rather than costs additional money because of the deficit problems that we have today, and I know that is the position of the administration.

Now, if you were in my position, what one legislative provision regarding home health care would you want to push to provide home health care for children?

Dr. DAVIS. I think, Senator, it is a little difficult at this point to put my finger on a specific activity. We have been trying, as I said, to encourage each of the States to develop either a regular home and community-based program waiver or a model waiver. All but two States and the District of Columbia have now done so.

We work very actively with the States. I have about 10 full-time equivalent staff people working with the States as we try to work through the approval process. And as I indicated earlier, we have developed almost a fill-in-the-blank model form, but we do find that it still is somewhat problematic in terms of the assessment process of what the costs would be.

Sometimes those costs are difficult to estimate, and I think that has been one of the major issues. But, second, and equally important, we have to make certain that we guarantee that the quality of care that is provided in the home is going to be equivalent and appropriate for the individuals.

We are still doing the evaluation. It would be a little premature for me, I think, at this point to give you——

The CHAIRMAN. Well, we would like whatever help you can give us because we do want to do this in this Congress.

Dr. DAVIS. We would be happy to work with your staff in providing further information.

The CHAIRMAN. Senator Nickles.

Senator NICKLES. Thank you, Senator Hatch.

Just one quick question. For the next panel, Dr. Davis, we are going to have, as you know, Katie Beckett's mother, and also Ruby Gaines, who is also the mother of a respirator-dependent child.

Is the State of Oklahoma 1 of those 19 States, do you happen to know?

Dr. DAVIS. No, it is not.

Senator NICKLES. Pretty much the same question that Senator Hatch asked—why would a State not—it seems to me like they would like to have that flexibility. It seems to me like they can save money and that they would provide better care, and it would be home health care instead of institutional care.

So why would a State not opt?

Mr. WREN. The State of Oklahoma, Senator, does have a regular home and community-based services waiver that has been approved, and they have a request in for another regular waiver. But the State of Oklahoma has not requested a model waiver, as was pointed out.

Senator NICKLES. OK. They have not requested a model waiver, but they did request the 2176 standard waiver?

Dr. DAVIS. That is correct, and the children can be served within that regular waiver program. I think that is an individual States decision as to whether they simply want to file for a larger waiver request which encompasses the aged as well as the children.

Senator NICKLES. Is the 2176 the broader——

Dr. DAVIS. It is a more comprehensive waiver program.

Senator NICKLES. And have they utilized that? Are a lot of States using that?

Mr. WREN. Yes, they have. We have had requests from 47 different States for the regular waivers, and for the regular waivers we have approved 88.

Senator NICKLES. You approved what?

Mr. WREN. Eighty-eight waivers from some 44 different States.

Senator NICKLES. Are those broad waivers on like individual cases or are they broad waivers for the States programs where the State could automatically place these individuals in home health care in lieu of institutional care?

Dr. DAVIS. It is the latter.

Senator NICKLES. The latter?

Dr. DAVIS. Yes. They make an estimation of how many individuals they believe can be served within the State, but it is far more than in the model waiver, which is limited to 50.

Senator NICKLES. I see. Do you feel like these programs are, one, better health care and, two, cost-efficient?

Dr. DAVIS. We do not approve of them unless they are cost-efficient, and I think one of our major concerns is to make certain that they are substitutional for the care that would have been given in an institution.

Clearly, I think from the group of individuals you have seen here today, it does represent a very important component. I think the growth and development aspects can easily be identified as being perhaps better in a home environment than they are in an institution.

Certainly, being a former pediatric nurse myself, I recognize that while institutions can give very fine care, there is no substitute for the family itself. We have tried, as I indicated, to stimulate interest in model waivers among the State Medicaid programs. They even at one point had Julie Beckett herself come and talk with the Medicaid Program people. So I think we have been very active in encouraging that particular program.

Senator NICKLES. Well, I commend you for it and I hope that the States throughout the country will take advantage of that, and I hope that you will continue to make it easy for the States through their applications. And through your statement, I was taking that you are, and again I compliment you for it and I appreciate your statement today.

Thank you very much.

The CHAIRMAN. Well, thank you so much. We know you have to catch a plane, so we will excuse you while we turn to Dr. Hutchins.

Dr. DAVIS. Thank you, Senator.

The CHAIRMAN. Thank you for being here.

Dr. Hutchins, I have to limit you to 5 minutes. You have an excellent 27-page statement.

Dr. HUTCHINS. Yes.

The CHAIRMAN. We clearly do not have time to hear it all, so if you could keep within 5 minutes and summarize, we are going to put your complete statement in the record, and we will for all witnesses.

Dr. HUTCHINS. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you so much.

Dr. HUTCHINS. We in the Public Health Service are grateful for this opportunity to appear with our colleagues from HCFA in presenting testimony to you about our efforts in support of effective health care for chronically ill and handicapped children.

In your letter of invitation, you asked that we discuss SPRANS grants. For those who are not up to date on Government acronyms, SPRANS stands for special projects of regional and national significance. These project grants are funded from a congressionally mandated setaside of moneys from the Maternal and Child Health Service's block grant enacted in August of 1981.

These special project grants are made for a variety of purposes and are intended to support and enhance the service delivery programs at the State and community levels. Grantees include health departments, voluntary agencies, professional groups, research centers, universities, and the like.

Before discussing current SPRANS activities, I believe it would be useful to discuss some of the background relevant to today's discussion, as well as the ways in which we look at our responsibilities and our approaches to the needs of chronically ill and disabled children.

We view our Federal agency rule as one of support—providing consultation, training and technical assistance to State and local health agencies, to education and other health-related groups, to health professional organizations, to volunteer and parent groups, and to other Federal agencies.

We feel our prime responsibilities are to support and assist with the design and development of a child-centered, family-oriented, community-based, State-coordinated, regionally organized health services delivery system for chronically ill and disabled children and their families.

This year, 1985, marks the golden anniversary of the passage of Public Law 74-271, the Social Security Act of 1935, which resulted in a 50-year commitment to the health and well-being of mothers and children.

Although one of the principal foci of title V of the Social Security Act—section 504, coincidentally—in 1935 was directed originally to children with orthopedic handicaps, State crippled children's programs have extended their concerns to physically disabled, sensory-impaired, developmentally delayed, and chronically ill children.

This comprehensive approach, 50 years in its development, is one which fosters the movement of children from institutions to the least restrictive, most appropriate setting for their development.

The concept of community-based services is certainly no current fad in health care. The goal of family-oriented, community-based services is to recognize a child as a local citizen with the rights and responsibilities of living, playing, growing, and developing in his or her own community.

When we restore children to their own families, schools and communities, they actively participate in the intellectual, social and recreational activities of their peers and receive health care from their own physicians.

Several events over the past decade have contributed to renewed interest in the service needs of children and youth—the emergence of Dr. Haggerty's concept of the new morbidities, passage of Public Law 94-142, the report of the study by the Vanderbilt Institute on the Chronically Ill Child, the report of the Select Panel for the Promotion of Child Health in 1980, and the Surgeon General's Workshop on Children with Handicaps and Their Families in 1982.

While participants from that workshop focused on the extensive problems of the ventilator-dependent child, the findings were extrapolated for their implications for all children with disabilities. Recommendations were given to the Surgeon General and many of the SPRANS grantees that we are reporting about this morning in the longer testimony are actually addressing six of those seven recommendations through projects supported by the Division of Maternal and Child Health.

Given this conceptual framework, background and the 50-year commitment, the Division of Maternal and Child Health has devel-

oped initiatives to address issues of regional and national significance in eight major areas relevant to this population: one, community-based services; two, early identification and intervention; three, youth in transition, the adolescent disabled youth; four, family enhancement; five, hemophilia regionalized programs; six, issues around financing of care for disabled and chronically ill children; seven new and emergent issues for special populations; and, lastly, the future of crippled children services to children with special needs.

All of these are closely related and the aim is to build an ongoing system of family-centered care at local and State levels. Beginning with the projects on ventilator-dependent children that were a direct outgrowth of the surgeon generals children's workshops and proceeding through the others, I will mention them briefly. References to them are in the main text.

We are currently funding three grants on ventilator-dependent children in the States of Illinois, Louisiana, and Maryland, and some of those you have heard from this morning. All three of these are focusing on transfer of children from institutional settings to homelike settings through the use of multidisciplinary teams.

Families are the most important support system for children who are chronically ill or disabled. Since most health care is provided by the family, families need to be encouraged to participate in all phases of their children's care and to serve as a resource for the health care team.

The issue of case management has come up this morning. The optimal case manager is the parent, and the professional case manager must be supportive of the parent in that role as the case manager. It is they who have the responsibilities of the child and who have to work their way through the system. The most we as professionals can do is assist that process.

There are a series of projects on financing. A project in Massachusetts as an example is Project Serve, looking at reorganization of the crippled children's program in Massachusetts.

Early identification is an important issue, and another project in Massachusetts is working through Children's Hospital of Boston and Wheeling College to look at followup of infants treated in newborn intensive care units within the six States of the New England area.

We are collaborating with the Department of Education on youth with disabilities—the problems of these children as they move to adult life and adult needs. Although we are concerned about the lack of resources for children, it is even worse as these kids move on into adult life and encounter educational as well as social, health, and vocational problems.

In addition to the projects mentioned there is the central issue of the future direction of services to be provided through State crippled children's services. The National MCH Resource Center at the University of Iowa is conducting a project that is examining the history of governmentally supported programs for children with specialized health care needs and is analyzing the following issues: services needed and the best methods to provide them; the barriers for obtaining these services; the organization of governmentally supported programs providing services at the State and local level,

with consideration of the feasibility of creating community-based networks of integrated services, and the financing of these.

Mr. Chairman, we believe that the SPRANS projects that we have the privilege to administer are making a substantial contribution to today's movement in support of care at home for chronically ill and disabled children.

We appreciate your invitation to describe these activities to you and your committee. Now, I would like to introduce to you Dr. Merle McPherson, who is accompanying me today. Dr. McPherson is chief of Habilitative Services Branch and she is responsible for the administration of the projects described and for many of the leadership efforts that these projects represent.

If you have questions about these programs or related activities, Dr. McPherson and I will be happy to try to answer them.

[The prepared statement of Dr. Hutchins follows:]

STATEMENT

OF

Vince L. Hutchins, M.D., M.P.H.

DIRECTOR

DIVISION OF MATERNAL AND CHILD HEALTH

HEALTH RESOURCES AND SERVICES ADMINISTRATION

DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

June 18, 1985

Mr.. Chairman and Members of the Committee:

We in the Public Health Service are grateful for the opportunity to join our colleagues from the Health Care Financing Administration in presenting testimony to you about our efforts in support of effective health care for chronically ill and handicapped children. I am accompanied by Dr. Merle McPherson, of the Division of Maternal and Child Health, Bureau of Health Care Delivery and Assistance. In your letter of invitation, you asked that we discuss "SPRANS" grants. For the benefit of those not up-to-date on government acronyms, SPRANS stands for Special Projects of Regional and National Significance. These grants are project grants, funding for which comes from a congressionally mandated set-aside of monies (the law sets aside between 10 and 15 percent) from the Maternal and Child Health Services Block Grant enacted in August of 1981. These special project grants are made for a variety of purposes and are intended to support and enhance the service delivery programs at the State and community levels.

Grantees include health departments, voluntary agencies, professional groups, research centers, universities and the like. Administration of the SPRANS grants is the responsibility of the Division of Maternal and Child Health in the Bureau of Health Care Delivery and Assistance, Health Resources and Services Administration. Before discussing current SPRANS activity, however, I believe that it will be useful to discuss the background for today's efforts as well as the ways in which we look at our responsibilities and our approaches to the needs of chronically ill and disabled children.

Conceptual Framework

We view our role, as a Federal agency, as that of a support organization, providing consultation, training and technical assistance to State and local health agencies, to education and other health-related groups, to health professional organizations, to volunteer and parent groups, and to other Federal agencies.

We feel prime responsibilities are to support and assist with the design and development of a child-centered, family-oriented, community-based, State-coordinated, regionally-organized health service delivery systems for chronically ill/disabled children and their families.

The year 1985 marks the golden anniversary of the passage of P.L. 74-271: The Social Security Act of 1935. Crippled Children's Services, one of the principal foci of Title V of the Social Security Act, was directed originally to children with orthopedic handicaps, but State Crippled Children's programs have extended their concerns to physically disabled, sensory impaired, developmentally delayed and chronically ill children and their families. Along with extending the populations covered, has been a concomitant effort to devise a comprehensive approach that is child-, family- and home-centered, rather than disease centered. This comprehensive approach, 50 years in its development, is one which fosters the movement of children from institutions to the least restrictive, most appropriate setting for their development. As often as possible that setting should be their own homes and cared for in their own communities. The concept of community-based services is certainly

no current fad in health care. The goal of family-oriented, community-based services is to recognize the child as a local citizen with the rights and responsibilities of living, playing, and growing in his own and communities they actively participate in the intellectual, social, and recreational activities of their peers, and receive health care from their own physicians. To be effective in both care and cost, services must be:

* Family- and child-centered in approach;
* Developmental in focus;
* Interdisciplinary in scope;
* Individualized, active, and ongoing in nature;
* Least restrictive in environment
* Comprehensive, continuous, and coordinated in execution.

History of Efforts

Several events over the past decade have contributed to renewed interest in the service needs of children and youth with chronic illness and to the needs and strengths of their families. One of these events was the emergence of the concept of the "New Morbidity"; in addition, there were: the passage of P.L. 94-142, the Education of All Handicapped Children's Act of 1975; the report of the study conducted by the Vanderbilt University Institute for Public Policy Studies on Chronically Ill Children; the report of the Select Panel for the Promotion of Child Health in 1980; the Surgeon General's Workshop on Children with Handicaps and Their Families in 1982.

In 1975, Dr. Robert Haggerty, one of the foremost leaders in child health,

noted that the social environment in which a child lives is a major determinant of his health and the care he will receive. The "New Morbidity" is characterized by children's behavioral and psychosocial problems and family stress. Dr. Haggerty described it as being beyond the boundaries of traditional medical care. The "New Morbidity" will require, Dr. Haggerty maintained, extension of the pediatrician into the community in collaboration with many other disciplines.

In the same year, Congress passed the Education of all Handicapped Children's Act (P.L. 94-142). Enactment of this law marked the culmination of a "revolution" in educational opportunities for handicapped children. More recently attention is being given to those children with health impairments such as diabetes, hemophilia, rheumatic diseases and cystic fibrosis, who do not require special education, but who do require related services. The concept of individual care plans, fostered by P.L. 94-142, has become accepted in all human services. Unquestionably, appropriate collaboration among the agencies and among providers of human services - health, education and social services, in response to these plans, is resulting in much more effective services for the patients and fewer complexities for the parents. Providing the least restrictive environment for children consistent with their special needs is another lesson from P.L. 94-142. This philosophy has opened the normal classroom to children with disabilities and chronic illness. However, we must not interpret "least restrictive environment" to mean "normal." Universal mainstreaming is as appropriate as blanket institutionalization for disabled children. The essential questions

should be, is the child being given every opportunity to learn or develop inherent abilities and have we, as a responsible society, removed all barriers and placed the child in the most opportune setting for development to occur? The Select Panel for the Promotion of Child Health issued its report in 1980. The chairperson, Lee Schorr, in her transmittal letter, said: "Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence on a child's health... From conception on, a child is dependent upon his or her mother and other family members not only for the physical necessities of life food, shelter, clothing and protection from harm - but also for the emotional support and intellectual stimulation needed for healthy growth and development. It requires no great expertise to recognize the importance to any child of a secure, loving and stimulating family environment... Our growing recognition of the psychological and social components of health has enhanced our awareness of the family's importance... The family is not only the principal influence upon a child's development, it is also the intermediary between the child and the outside world, including the health care system... Health providers can support encourage and enhance the competence of parents in their role as caregivers, or they can directly or indirectly undermine and denigrate it."

Four themes emerged from the Select Panel's review of the health care needs of children with chronic illness: First, the necessity for coordination of care with elimination of duplication and unnecessary categorical restrictions; second, the requirement for more training of professionals at

all levels; third, the need to support and expand prevention and early identification efforts; fourth, the necessity to secure more psychosocial and financial support for families of chronically ill children.

Since the late 1970's the Vanderbilt Institute for Public Policy Studies has been examining the themes enunciated by the Select Panel, as well as other issues, through their Chronically Ill Child project. It is important to note that this project was funded jointly by the Departments of Education and Health and Human Services in the public sector and by the Robert Wood Johnson Foundation, in the private sector. The Vanderbilt investigators identified certain basic principles that should underlie policy concerning chronically ill children, including:

* "Children with chronic illnesses and their families have special needs which merit attention, beyond that provided to the health needs of able-bodied children.

* Families have the central role in caring for their own members and the goal of policy should be to enable families to carry out their responsibilities to nurture their children and encourage their most effective development.

* Policy should encourage professional services of a highly ethical nature. Key elements include truth telling, confidentiality, maintenance of dignity and respect for family preference, professionals' recognition of limits of their own effectiveness, and emphasis on collaboration."

The Surgeon General's Workshop on Children with Handicaps and Their Families,

in December 1982, gave prime consideration to high technology, its contributions, its complications and its high cost.

The major objectives of the Surgeon General's Workshop were:

* To develop strategies to recognize the comprehensive services and long-term assistance needed by children with disabilities;

* To address the burdens and challenges faced by the families of these children;

* To stimulate the provision of resources for these special children in their communities;

* To address the burdens and challenges faced by the families of these children; and

* To stimulate the provision of resources for these special children in their communities.

While Workshop participants focused on the extensive problems of the ventilator-dependent child, the findings were extrapolated for their implications for all children with disabilities. Seven recommendations were presented to the Surgeon General:

* Define the Scope of the Problem
* Develop Model Standards
* Develop Systems of Regionalized Care
* Improve Financing of Care
* Identify Areas of Abuse Potential
* Incorporate Into Training Curricula Principles of Care for Children with Disabilities
* Support in the Care of Children with Disabilities

The Surgeon General's Workshop and the recommendations that emanated from it stimulated a variety of activities and projects designed to address and implement them. SPRANS grants have been awarded to organizations that addressed six of the seven recommendations and the Division of Maternal and Child Health continues to work with the Surgeon General to improve the delivery of services and to develop and disseminate information about available services for chronically ill and disabled children and their families.

As President Reagan noted in his Child Health Day, 1984, message: "There ...are severely handicapped infants who require not only the love and support of their families but who must have the help of many groups in their communities--doctors, hospitals, health departments, providers of health care, and others--if they are to thrive.

During the coming year, it is my hope that we can continue to demonstrate what a free, energetic, and enlightened society can do cooperatively to protect and improve the health status of our Nation's most vital asset, out children."

SPRANS Experience

Given this conceptual framework, background and 50-year commitment, the Division of Maternal and Child Health has developed initiatives to address issues of regional and national significance in eight major areas: (1) Community-Based Services Development; (2) Early Identification and

Intervention for high-risk infants and those with discernible handicaps; (3) Youth in Transition/The Adolescent disabled Youth; (4) Family Enhancement; (5) Hemophilia Regionalized Program; (6) Financing of Care for Disabled/Chronically Ill Children; (7) New and Emerging Issues for Special Populations; and (8) Future of Crippled Children's Services to Children with Special Needs.

All are closely linked and the aim is to build an ongoing system of family-centered care at local and State levels. Beginning with the projects on Ventilator-Dependent children that were a direct outgrowth of the Surgeon General's Workshop and are representative of new and emerging issues for special populations and proceeding to discuss those projects related to Financing Health Care, Community-Based Services, Early Identification and Intervention, Youth in Transition, Hemophilia, Family Enhancement and Future of Crippled Children's Services, let me describe a few projects and offer to provide the committee with additional information, if requested.

Ventilator Dependent Projects

The Division of Maternal and Child Health funded three grants to develop systems of regionalized care focusing on ventilator-dependent children. The grants were awarded to Illinois, Louisiana, and Maryland. All three projects focus on the transfer of children from institutional settings to home-like settings through the use of multidisciplinary teams.

The projects are concerned with providing comprehensive, cost-effective, continuous care to children with high-technology needs. They require extensive collaborative effort by tertiary, intermediary, and primary care agencies. All three projects emphasize the need to develop and sustain a community-based support system. The Maryland project combines local, State, and regional organizations to establish a private, non-profit organization to facilitate the discharge of ventilator-dependent children to their parents or guardians for care at home. Collaboration may involve cooperation of tertiary pediatric emergency medical services, local fire department and voluntary ambulance services, or parental training provided by community agencies and private practitioners.

These projects are collaborating in developing educational materials for families and professionals; in developing forms to collect similar data on the number of children who are technology dependent, helping to define the scope of the problem; and in providing information about some of the long-term consequences of disabling conditions on these children and their families. The University of Chicago received a SPRANS grant to evaluate the economic and psychosocial impacts on families of caring for their ventilator-dependent children at home and to determine the appropriateness of the three State programs for use in communities with other types of chronically ill/disabled children.

Financing Health Care Projects

Problems related to financing care were cited in the report of the Surgeon General's 1982 Workshop on Children with Handicaps and Their Families,

mentioned earlier. These problems were cited as unfortunate side effects of recent improvements in health care. We have discovered that today's sophisticated technology is not only costly, but seems to require that children be kept in institutions, away from their families and homes. The Division of Maternal and Child Health has encouraged, supported and initiated PHS activities in collaboration with other agencies in the Executive Branch, including HCFA, and in the private sector to address the recommendation to improve the financing of care that emanated from the Surgeon General's Workshop.

Presentations in a 1985 meeting of an ad-hoc group on financing health care for chronically ill and disabled children focused on 10 SPRANS projects which related to various aspects of the financing issue.

The projects, by State, include:

- Developing a Computerized Information System [California]
- Evaluation of Utilization, Expenditures ad Sources of Payment for Care of Chronically Ill/Disabled Children and Their Families [California]
- The Network of Services [District of Columbia]
- Case Management Consultation Evaluation [Florida]
- Standards of Care [Iowa]
- Future Directions of Care in CCS [Iowa]
- Identification of Data Needs [North Carolina]
- Coordination of Care [New York]
- Estimates of Costs of Care for Six Conditions [New York]
- Financing Nutritional Services [Utah]

Our expectation is that our continuing activities related to Financing Health Care of Children with Chronic Illness and Disabling Conditions will focus on five related areas: (1) The impact of Diagnosis Related Groups [DRG]'s; (2) Data Needs; (3) Liaison with Health Care Financing Administration [HCFA]; (4) Liaison with Private Insurers; and (5) Future Roles for State Crippled Children's Service [CCS] Programs.

Community-Based Projects

The purpose of the Network Project of Georgetown University Child Development Center project is to provide key assistance to States in implementation of policies and programs to facilitate local coordination efforts for children with disabilities and chronic conditions and for their families. It is the culmination of a number of Federal interagency efforts aimed at improving comprehensive care across agency and professional lines. At the Federal level, it includes collaboration with the Office of Special Education and Rehabilitative Services; the Health Care Financing Administration; the Headstart Bureau of the Administration on Children, Youth and Families; the Administration on Developmental Disabilities; and the National Institute of Mental Health. Currently 31 States are a part of the network with Technical Assistance and consultation provided to education, health and mental health

agencies as well as to public and private voluntary groups. California recently hosted a meeting of 7 western States from the network. Two major problems discussed were (1) how to get psychosocial services to children in local communities and (2) how to finance this care.

In Iowa, the "Networking of Services for Handicapped Children" project is one that was established to develop in-state regional networks of care for children with chronic conditions. Programs formerly administered by the Federal government are now State-directed with and receive appropriate input from their communities. Regional networks are intended to coordinate available services needed by chronically ill children and their families. The program has begun with the initiation of a data/information system to facilitate interagency communication and evaluation of care delivery systems.

The project will increase knowledge concerning the needs for services and outcomes of services, will create a more effective method for provision of services through inter-organizational cooperation, and will demonstrate a new model for collection and analysis of multiagency data used for evaluation and planning. The next phase of this grant will be spent in consolidating support services for chronically ill children, in developing a continuing education program for Network Integrated Evaluation and Planning Clinics, and in providing multiprofessional agency medical counseling and treatment services for adolescents. A study of methodology and approaches employed will be published at the end of the second year of grant support for dissemination to States outside the demonstration region.

Project SERVE was funded through a SPRANS grant to the Massachusetts Tri-Agency Project for the Development of Policy and Program Strategies for Handicapped Children and Their Families. It is a program devised by three organizations: Division of Family Health Services Massachusetts Department of Public Health; the University Affiliated Program fn the Boston Children's Hospital, and the Department of Maternal and Child Health and Aging in the Harvard School of Public Health to design and implement a State-wide comprehensive system of care for handicapped and chronically ill children and their families. The tasks at the initiation of Project Serve were needs assessment and policy analysis and implementation of a comprehensive system through consultation and technical assistance to the Division of Family Health Services. The most recent phase of his project has involved the development of strategies for alternative models for financing and for health care delivery. Project Serve was formulated as a review of the operation of the State Clinic system, and is to assist the Division of Family Health Services in defining its present and future role in service delivery to this population.

In addition to the intentions stated above, Project Serve will develop linkages with other public and private service providers and will help to devise strategies to implement alternative models for financing and delivery of health-care services for chronically ill children in the State of Massachusetts.

Another important program is the "Community Health Care for Children with Chronic Conditions" project, centered at the Gillette Children's Hospital in

St. Paul, Minnesota. This program is an interdisciplinary, multifacility project to stimulate the development of comprehensive community-based services for this population. The program emphasizes three approaches: (1) The development of a regional consortium composed of professional disciplines, institutions, and public and voluntary categorical disease agencies. The consortium is a study group for exploration and facilitation of cooperative efforts, (2) The diversification of community-based activities by programs with expertise in chronic disease, and (3) The analysis of current patterns of health-care financing. Addressing as it does effective regionalized systems of health care, community support systems, and improved methods of financing of health care through documentation and analysis in order to develop comprehensive State care-financing plans, this project is expected to produce findings of major, national significance.

Another project is the "Coordination of CAre for Chronically Ill Children," conducted by Health Research, Inc.. and the New York State Department of Health in Albany, New York. The general purpose of this program is coordination of care among medical entities and voluntary support organizations and the delivery of specialized team care for various chronic illnesses of children. The program will establish demonstration projects as coordinated, comprehensive service model, and will see to the coordination of plans in the Department of Health and other agencies. Importantly, it will establish a data system of numbers of children, age, condition, and location of care. Regional workshops throughout the State and feasibility studies on the nature and scope of the problem will be additional methods of procedure.

Early Identification and Intervention

Early identification and intervention for high-risk infants and those with discernible handicaps is vital for effective care-giving and favorable outcome. Working closely with the Office of Special Education and Rehabilitation Services/Special Education Program, the early intervention program for children, birth to three years of age, is of importance in the planning, development, implementation and establishment of appropriate health and education services for children with, or at risk of, disabling conditions and chronic illnesses. Informal and formal networks and collaborative efforts among Federal, State and local governments; private and voluntary organizations; private practitioners and parents serve as effective mechanisms for reaching goals in this area of concern. SPRANS projects in this category include:

Project ACCESS, in Massachusetts, has worked with the six New England States to examine access to follow up and Early Intervention services for infants at risk once they leave neonatal intensive care. We are sharing information and knowledge gleaned from the project with many other States, including the States of Oklahoma and Utah.

Another exemplary project is "Project 0-3," a SPRANS grant to the National Center for Clinical Infant Programs that provides a mechanism for selected STates to improve services for at-risk and disabled children and their families in the first three years of life. It provides a

framework for training; sharing of information and experience among States; development of materials and concepts relevant to the current needs of State programs; and consultation services to address specific issues raised by States. Working initially with 10 selected States: Maine, New Jersey, Maryland, North Carolina, Ohio, Texas, Iowa, Utah, Hawaii, and Washington, the project is designed to have a national impact on improving services to this special population of children. Its interdisciplinary staff has become a national resource and network for information and assistance to health professionals, parents and policy makers concerned with the needs of disabled and at-risk infants, toddlers and their families.

Youth in Transition

In recognition of the fact that pediatric needs are different from adult needs, the Departments of Health and Human Services and Education a collaborated to convene a conference on, "Youth and Disability: The Transition Years." This project was developed in response to a pressing need for the provision and coordination of health/education/vocational and social services for adolescents with chronic diseases or disabilities. The goal was to identify major barriers to service and to develop strategies for overcoming them through research/policy/legislation and programming. The proceedings of this conference were summarized in the March, 1985 issue of the Journal of Adolescent Health Care, and focused on looking at long term care problems in moving from child to adulthood and at answering the questions, "How can we make children more self-sufficient/employable, and thus avoid long-term dependency costs?

Hemophilia as a Model Program

In 1975, Congress established the comprehensive hemophilia diagnosis and treatment center program, providing direct federal funding to support the development of 22 comprehensive hemophilia centers and 60 affiliates. With support from the Division of Maternal and Child Health, the network of centers has expanded and it now provides a strong regional structure. Now SPRANS grant supported, the impact of these programs has been dramatic. Over 9500 hemophilia patients (nearly 50% of the total hemophilia population) are now served by these centers, providing multidisciplinary services including psychosocial, financial and vocational counseling, in addition to medical, dental and orthopedic care.

We believe that this Federal investment in comprehensive care programs that promote home infusion has paid off by reducing disability, unemployment and the cost of medical care for hemophilic patients.

Family Enhancement Projects

Families are the most important support system for children who are chronically ill or handicapped. Since most health care is provided by the family, families need to be encouraged to participate in all phases of their child's care and to serve as a resource to the health care team. Each SPRANS project supported by Division of Maternal and Child Health acknowledges the importance of a parent professional partnership in the habilitation of infants and children with chronic illnesses and is asked to take identifiable

steps to enhance the participation of parents. A workshop on, "Families As a Critical Factor in Prevention," conducted by the University of Pittsburgh, set a course of action for improving family involvement and improving psychosocial services in Title V programs. As a part of the followup, a new policy statement on family participation is being prepared by DMCH and will be disseminated widely. This statement will emphasize the following principles and approaches:

- knowledge, development and use of family strengths
- consideration of family needs balanced with patient needs
- unbiased and complete information sharing about resources, prognosis, and pros and cons of treatment choices
- connecting and helping to maintain the connection of parent to parent networks.

Therefore, services should be organized so that they:

a) recognize the unique strengths of individual families;

b) incorporate child and family developmental services within the health care system;

c) facilitate the family's involvement in planning, implementing, and evaluating those services; and

d) remove obstacles in the current delivery system.

The DMCH is carrying out this family initiative through the following projects and activities:

Maryland Division of Crippled Children's Services - development of a model parent counseling and education project in preventive health services and

early intervention for children at risk for developmental delay due to medical or psychosocial factors.

Focus Inc.., Jonesboro, Arkansas - a model project in a rural area demonstrating competency-based parenting skills for handicapped and special needs mothers working with handicapped children.

Colorado Department of Health - to increase the accurate identification of and intervention with those families with handicapped children most in need of psychosocial intervention.

University of California, San Francisco - development of a regional network of services for families with chronically ill children, including parent support groups, a family assessment team and education workshops for children and families.

Other activities to promote the family initiative include:

- interagency collaboration with OSERS national network of parent information centers
- an interdisciplinary, interagency advisory panel, including parent representatives, on family participation and psychosocial issues in the Division of Maternal and Child Health
- parent and psychosocial initiatives in the hemophilia program with a special focus on AIDS, and
- parent and family activities with the juvenile arthritis groups.

Future of Services to Children with Special Needs

In addition to the projects mentioned in this testimony is the central issue of the future directions of services to be provided through State Crippled Children's Services. The National Maternal and Child Health Resource Center of the University of Iowa is conducting a project which is examining the history of governmentally supported programs for children with specialized health care needs and is analyzing the following issues:

- the services needed and the best methods to provide them;
- the barriers to obtaining these services;
- the organization of governmentally supported programs providing services at the State and local level with consideration of the feasibility of creating community-based networks of integrated services;
- the financing of these services.

This project and its multi-faceted report will deal with the major problems of the State Crippled Children's Programs--the lack of coordination between State Crippled Children's Programs, as well as the fragmentation of services for handicapped and chronically ill children; the problems of casefinding and serving remote areas; inadequate reporting systems; and the funding of health related services in the face of increasing medical care costs. A national report will be published to enunciate goals and objectives and to furnish guidance to State Crippled Children's Program administrators, to State and local public policy makers, and to other organizations, groups, and individuals responsible for or interested in the delivery of services to these children.

This report will synthesize the knowledge and information we are gaining from many of the aforementioned SPRANS efforts in the hope of providing answers to the complexities of organizing and providing services to children and to their families in their own homes and communities.

In our discussion today, we have focused upon a number of activities which illustrate our activities and concerns with respect to chronically ill and handicapped children. Other current projects include a research project which seeks to discover improved methods for insuring healthy growth and development in low-birth weight infants; a group of interdisciplinary training projects which prepare health professionals to deal with very complex child developmental problems; as well as projects supportive of regionalized systems of perinatal care, adolescent health, nutritional services, and many other programs.

Rather than summarizing the accomplishments of SPRANS projects, or restating our philosophy and goals, I would like, briefly, to describe for you the history of Jonathan. Jonathan's story is one of success - and of the very hard road one sometimes has to travel to achieve it. I think also that it illustrates in a very real way, the complexities, the difficulties-- and the opportunities that we encounter when we deal with the really tough problems of chronic illness and severe handicaps in infants and small children.

Jonathan: A Success Story

A case study of a family-oriented, community-based approach to delivering comprehensive services serves to illustrate both the complexity and the efficacy of using such an approach to provide needed care for chronically ill and disabled youngsters.

Jonathan was born at a gestational age of 28 weeks (3 months before term). After five months in the Neonatal Intensive Care Unit at the University of Washington in Seattle, he was discharged home to Jefferson County Washington. As part of a SPRANS grant on Early Intervention to the Washington State Health Department, Jonathan and his family were provided the developmentally focused services of a clinical nurse specialist from the Jefferson County Heal Department. A member of a team composed of neonatologists, neurologists, ophthalmologists, nutritionists, pediatricians, nurses, social workers, physical therapists, and other health professionals responsible for overseeing Jonathan's welfare. Although Jonathan had gained enough weight (discharge weight of 5 lbs. 1 oz.) and his clinical status was improving, his list of health problems was long: prematurity, retinopathy of prematurity, interstitial respiratory distress syndrome, potential seizures, patent ductus arteriosus, necrotizing entercolitis, and an ileostomy. His parents came to Seattle where the Neonatal Intensive Care Unit was located and lived there while Jonathan was hospitalized. They were both young and the father made a meager living by seasonal fishing.

After discharge, the family was seen frequently by the nurse. The early contacts were focused on Jonathan's survival. he was fed through a tube. His nights and days were the same, the parents had to feed him every three hours around the clock. Due to his fragile state, he contracted pneumonia and was rehospitalized at the pediatric hospital in a distant city. All this time, the nurse was in contact with all services used (pediatric care, ophthalmology, neurology, gastroenterology, nutrition and CCS).

Three months after initial discharge, when Jonathan was 8 months old, the nurse and physical therapist instituted a home-based intervention program. They taught the parents how to position Jonathan and to do passive range of motion, since Jonathan had abnormal muscle tone. Observations made it increasingly clear that Jonathan would probably be diagnosed as having cerebral palsy. This is a common aftermath of intercranial hemorrhage in premature babies.

After several more bouts of ear infections, treatment with antibiotics and ear tubes finally saw Jonathan into a wellness period. Jonathan was well enough by 9 months after coming home to get the immunizations that usually start at two months.

The developmental intervention continued on a weekly basis through the first year. During this time Jonathan was growing, and making developmental progress. The parents were finally able to resume a more normal life. The father returned to work, however, his fishing job kept him away for weeks at a time. His absence shifted the whole burden to Jonathan's mother. Finally, the nurse was able to secure vouchers from the State which would pay for respite care. This care for several hours or even a day at a time was extremely important for the mother's physical and mental well being. At one point, when the respite care was not available, due to a licensing problem with the respite care home, the mother said, "Tell them I'll commit suicide if I don't have some relief."

Careful monitoring of growth continued, particularly weight and head size. Finally, at about one year, the ophthalmologist gave the family good news. The retinopathy of prematurity had resolved. Jonathan still had extremely weak eye muscles, that the ophthalmologist was hopeful would normalized by four years of age.

The parents were fast losing tolerance for the rate of Jonathan's progress at the end of the first year. As they saw other children walk and talk, they needed extra support to express and deal with their disappointment and anger. During this period they cancelled visits. Persistent efforts by the nurse and physical therapist finally helped the parents continue their important role as the daily caregivers and developmental interventionists.

Through the State of Washington, it was possible to enroll Jonathan in a center-based Early Intervention program, several days a week. The parents drove a total of 120 miles each time to take Jonathan to the facility. Finally a play group at the local Junior College accepted Jonathan. Here Jonathan and his family were able to continue with developmental guidance; however, the new program again prompted the parents to deal with their anger and frustration with Jonathan's problems. The normality of other children was difficult to accept. Again, the nurse listened and counselled the parents.

Jonathan then developed septicema, during his second year of life, from an upper respiratory infection and had to be airlifted to a larger medical center. He had seizures at this time and was followed again by the

neurologist and put on medication. The parents were near despair. They sought the advice of a naturopath. He convinced them to take Jonathan off phenobarbital and to give oral calcium. After much consultation with a nutritionist at the State University's SPRANS supported Child Development and Mental Retardation Center, and with the attending neurologist, the nurse was able to bring the parents enough information to help them accept the prescribed treatment and not abandon it for the naturopathic treatment. The consistent work of Jonathan's parents and the extensive and sophisticated care from many, many health professionals now is paying off. At four years of age his developmental progress continues. He is in a normal 3-5 year pre-school group. The latest prediction is that while he will continue to have a significant motor problem, he is expected to eventually walk and attend a regular school program. Jonathan's parents have become strong advocates for him.

Jonathan's is a success story written by his parents and the many health care professionals on the team. It demonstrates once again as President Reagan said, "...What a free and enlightened society can do to protect and improve the health status of our Nation's most vital asset, our children."

The CHAIRMAN. Thank you very much. Dr. McPherson, thank you very much for being here. I was going to recognize you before. You do a great deal of good, very effective work in the area of SPRANS grants. We appreciate that.

Let me just ask one or two questions. Based on your experience so far with SPRANS grants, what specific new Federal health legislation would you recommend or would be most likely to be helpful in helping these children?

Dr. HUTCHINS. I think the financing needs are very important, and I thought it was interesting this morning when you asked the parents what their most pressing need was, that it was financial assistance which was identified.

There is an implication in that answer that the services are out there to purchase. We have some concern that, while they may be there, they are not always readily accessible or are not coordinated in a very effective way. As a result I think, in addition to the financing of the services, the need to have the services put together at the community level to support the families is the second most pressing need within this field.

The CHAIRMAN. OK, thank you. Critics of expanded home health care services cite concerns that we will create an opportunity for more abuses in federally funded entitlement programs.

From your research, can you recommend how fraud and abuse can be limited or how excessive costs can be limited?

Dr. HUTCHINS. I think what we have learned over the last few years is that the involvement of parents in program planning and evaluation and administration is one of the main efforts that is going to keep all of us honest in many ways—ways even, that are beyond the use of funds.

The CHAIRMAN. Well, thank you.

Senator Nickles.

Senator NICKLES. I do not have any questions, Mr. Chairman.

The CHAIRMAN. Well, thank you so much, Senator Hutchins—I called you a Senator. We are demoting you. [Laughter.]

Dr. Hutchins and Dr. McPherson, thank you so much. We appreciate you being here today and appreciate this testimony.

Dr. HUTCHINS. Thank you, Senator.

The CHAIRMAN. Thank you for being with us.

We will now turn to our last panel and I want to thank Ms. Julie Beckett and her daughter, Katie, for being willing to wait this long. Our third panel will begin with Ms. Julie Beckett, who will share with us her experiences in obtaining a Medicaid waiver for home health services for her daughter, Katie.

We are also going to hear from Ms. Debbie Berry, a nurse in Oklahoma. Ms. Berry is accompanied by Ms. Ruby Gaines, whose son, Marvin, is currently respirator-dependent and receiving home care services.

I want to thank you for coming from Oklahoma to be with us today. We understand that Senator Nickles has been tremendously helpful and supportive to you in obtaining the attention that Marvin Gaines has needed, and we are very proud of him and proud of the work that he does on this committee.

Is Ms. Beckett here? She is coming in, I see.

Senator NICKLES. Mr. Chairman, I might add while we are waiting for the Becketts that Debbie Berry had contacted our office concerning the plight that Marvin Gaines found himself in. He is a quadraplegic from a bicycle accident. The young man is now 15 years old. I have a 15-year-old as well, so I am more than sympathetic with your plight.

I am impressed with Ruby Gaines, Marvin's mother, who is with us as well, and very impressed with Debbie Berry's efforts to help some of the youngsters and people who find themselves institutionalized return to the family environment.

I am pleased to hear Dr. Davis say that HCFA is working to help make exceptions, and I want to make sure that those exceptions are being granted, I guess, in our State and other States to where we can help these children return to a home environment.

And to the Becketts, I want to thank them because they were leaders nationally in helping to get some of these exceptions made. So I compliment them because through their efforts and their story, they have helped a lot of youngsters throughout the country.

The CHAIRMAN. Well, thank you, Senator. I appreciate you helping me with this hearing because I could be yanked out of here any minute because I have been trying to alternate between two hearings, both of which are extremely important to the country, to me, and I think to you.

Ms. Beckett, it is great to see you again. I will never forget your testimony out in Salt Lake City; it meant so much to me then. And it is great to see Katie here with us, too. So we will begin with you.

If you could pull that one microphone over so we can hear you, we will take your testimony first.

Thank you again, Senator, for helping me with this hearing. If you could finish up, I would appreciate it.

STATEMENT OF JULIE BECKETT, CEDAR RAPIDS, IA; AND DEBBIE BERRY, OKLAHOMA CITY, OK, ACCOMPANIED BY RUBY GAINES, OKALHOMA CITY, OK

Ms. BECKETT. Well, thank you, Senator Hatch. I also appreciate being able to address this committee again. The last time that I was asked to speak to this particular committee, Senator Hatch wrote a wonderful poem about Katie and about Mark and about our kind of children. And I would like to thank the Senator, also, and let him know that it is framed and sitting at home on the wall.

The CHAIRMAN. That may be the only poem of mine that has ever been framed. Thank you so much.

Ms. BECKETT. Thank you, Senator. I will begin by reading my testimony.

Members of this committee, we appear before you today as a family—a typical, all-American, middle-class family. You may say not so typical, but on the outside, on the surface, that is how we look; mother and father, fairly intelligent, college educated, broad range of interests, in fairly good physical shape; daughter, 7 years old, second-grader, Brownie, pretty, intelligent, inquisitive and rambunctious.

The CHAIRMAN. Mr. Beckett, do you agree with all those?

Mr. BECKETT. Yes.

The CHAIRMAN. I am sorry I did not recognize you. I get so dominated by Katie that I fail to recognize you every time we have a hearing, and I apologize.

Mr. BECKETT. I am used to it.

The CHAIRMAN. You are used to that. Go ahead.

Ms. BECKETT. Something is different. She has a funny necklace on and she carries a bag. I think it is a gym bag, not a purse. Those who look more closely can see the love and the caring shared by this family, but few people can see the sadness, for nowadays there is little sadness.

They surround themselves with happy things—time shared, as most families do, with picnics, travels to grandparents' houses, lessons to be learned, television shows to be watched, prayers to be said, and vacations to go on.

But are you getting the real picture? Why is she wearing that necklace? Let me give you some reasons. She cannot breathe while she sleeps without a mechanical device to help her. She needs three treatments a day which mom and dad perform to keep her lungs clear. A machine follows her wherever she goes and a person who knows how to operate it.

Finally, that little gym bag is filled with catheters, gloves, syringes, food, medication and, most importantly, a gastrostomy tube, a trach, and an ambu bag.

You see, she is what the experts, the professionals, call a medically fragile or a medically vulnerable child—words that every time I say them seem more and more unusual. Oh well, then she is not your typical middle-class American child? Do not count on it.

Today, because of all the new things introduced in our lives in the last 30 to 40 years, along with the successes come some of the failures. Along with the good comes some of the bad—more severe illnesses, more complex illnesses, and new and wonderful ways to treat them.

Our society is changing; our society has changed. It is coming of age and we have to prepare for it. You are the people to help that change.

We are still the typical middle-class American family, but we have been given a reprieve. We went through the sadness, the heartache, the illness, and we are fighters. We met the dragon, we looked him in the eyes, and we have defeated him, maybe. My father always says give yourself an out.

This whole trip was almost canceled because that evil thing called infection came to call on us a week ago. But as I said before, we are fighters; clarified, Katie is a fighter and she has two good people in her corner who gear up every time something looks funny.

It takes a simple call to the doctor's office and the force is with us, never discounting the Hail Marys and the Our Fathers that fly off in between.

But let us get back to what makes us different. We are not so different. We want our child to grow up in the most normal fashion possible, in her home, in her bedroom, in her classroom, in her Brownie day camp—all things provided because people named Ronald Reagan, George Bush, Richard Schweiker, but most assuredly Tom Tauke, Jane Hart and Hazel Wharff, one of our dear-

est friends, and a man that few people will remember as being instrumental in our getting home, Daniel Schorr. Interesting?

I will never forget when he stood up at the end of that news conference and clarified what the President had said before about hide-bound regulations, because I knew that would seal our package home. And I will never forget meeting one of the six men who worked for 72 hours to find that little section in the Omnibus Reconciliation Act of 1981 which would apply to our case—our friend, Fred Abby.

I can never express how grateful we are to each and every one, and to the hundreds of others who have the same opportunity because the door was open and caring people like Surgeon General Koop, Margaret Heckler, Dr. Carolyne Davis, Dr. Merle McPherson, Dr. Vince Hutchins, Camille Cook, Bob Wren, Bob Wardwell, Dan Converse, Fred Abby, Michael Batten, and hundreds of others were waiting to help, not to hinder.

These people, especially the last four, have done more to help the model waiver and the home and community-based waiver succeed, and certainly they have been successful. But there is still a long road to hoe.

I cannot speak today without mentioning the people who have tried so hard, but they are too many in number. Some of them, however, are here and should be recognized; Tammy West and Patti Bearpaw, who, as mothers, fought for the waiver in New Mexico; Marguente Nikol, who unfortunately could not be with us today because of her very sick child, who almost solely convinced the State of New York, the Governor, the State Medicaid director, the whole social services system, that children in New York can live outside a hospital if they had a waiver.

Helen Clark, a mother who would not relinquish her hold on the Texas Medicaid Department until they finally gave in and applied for the waiver.

Bette Wingel, who lived desperately for years until they were finally able to secure an individual waiver for their late daughter, Judy.

And Karen Shannon, my ally and my friend, who helps more people by support and by utilizing the resources she has, who has helped to develop the Maryland waiver and the entire SPRANS grant project in Maryland. Unfortunately, they did not let her run it or we would have more kids home. She is the founder and director of SKIP.

These people are recognized as SKIP—Sick Kids (Need) Involved People. They are here to support the thousands of children still in desperate need of our support.

Has the waiver been effective? As I speak around the country, a resounding yes comes to the fore, but is it enough? What do families need? What do these taxpayers need? There are more families than you can count who have insurance—insurance that will run out soon.

Have you ever been in a situation where someone who is ill eats up hundreds of thousands of dollars every year? Hopefully not. Well, we have, and we prepared for it. We carried good insurance—million dollar policies that ran out in a very short period of time. Then what is the answer?

The answer lies in a cooperative effort. Public and private funders, State insurance commissioners, major self-insurance companies must come together to meet and solve the problems plaguing a great number of families in our situation.

The Medicaid system cannot encompass all these children, and they should not have to. We work hard to pay taxes, but we also continue our health insurance and we deserve an even break just like everybody else.

We must, as a society, produce a new alternative to health coverage for the technology-dependent child and his or her family. We are not unique anymore. Our numbers are growing in leaps and bounds.

As parents, we want to share the responsibility for our children and their lives. It is frightening as a parent to have a child with a wonderful potential for a successful life facing no health insurance coverage whatsoever. You would not live without it. Why should they have to?

Why build a society dependent on welfare? Do we not already see the ramifications for that? These parents and the professionals who care and develop programs for them want to voice their needs, and we can as a society do more to move ahead. Understanding has begun amongst our peers, amongst the health care professionals, even amongst the funders and, believe me, not without a lot of sweat and tears.

I went on my own and with others to educate many persons from the Health Insurance Association of America, Blue Cross-Blue Shield, American Hospital Association, many Members of Congress, many members of HCFA, both State and Federal agencies, and many members of HERSA, just to name a few.

We have agreed we can help, we can work together, but we need the opportunity to come up with a solution. The Federal Government's responsibility should be to provide a forum for this and incentives to achieve this.

Until this meeting, this consensus, this forum takes place, we must support what we have. The waiver program can and should continue. The successes of Dr. Davis, Fred Abby, Dan Converse, Bob Wren and Michael Batten must be saluted. They have done everything to convince the States that the waiver programs will help these children. The States who have complied and those who are complying should be saluted, and those States who have not should be convinced to help.

It should not be more costly. How can it possibly be when children are at home and being cared for by their parents, even if those parents have help in the home? Room and board alone save many dollars.

Help us. We will continue to educate, but you must help us. These are not the only problems which face our new generation. Quality assurance guarantees, professional training are among others, but those are being dealt with, again, through education—our educating them. But without the financing, we cannot do any more. We must settle this problem which can be resolved.

Help us. We will do it; we must. They are our children, the hope for the future. The future lies in their hands. Let us prepare them for it.

I would like to conclude my testimony this morning. I have prepared a few recommendations for the committee. One, I believe the individual waivers need to be reinstated to handle cases which need immediate attention. Some of these families do not have long periods of time before their little ones are reinstitutionalized after private insurance has run out.

I believe a person should be designated within the Department of Health and Human Services to handle these particular cases.

Two, I also feel the role of Congress and the Federal Government in general is to provide an incentive to the States to apply for model and home and community-based waivers. I feel that seat belt regulation laws have worked very well with such incentives, and I feel that such incentives to save family lives are just as important.

And last, and probably most important—I cannot stress this enough—I feel a task force, a commission, must be established, bringing public and private funders together in a cooperative effort to come up with new alternatives to funding health care for this medically fragile, technology-dependent society.

From this, I feel an information base can be reached to provide reduced health care costs for chronically ill persons across the board. This collaboration between the public and private sectors is the only way we can face the problem of financing care for this new generation.

I thank you.

The CHAIRMAN. Well, thank you, Ms. Beckett. You were, as you were last time, very eloquent, and we appreciate the recommendations you have made to the committee.

Ms. BECKETT. Thank you.

The CHAIRMAN. Ms. Berry, we will turn to you now, and we are happy to have you here as well, Ms. Gaines.

Ms. BERRY. I would like to begin by saying I appreciate the opportunity to be here. I appreciate Senator Nickles' office and all the work that he has done to help Marvin and other kids in the State of Oklahoma, and also in allowing us to be here today to speak with you.

I am a registered nurse at a hospital in Oklahoma. I deal specifically with ventilator-dependent children. I think because of the recent advances in our medical technology that we will continue to see children such as these living longer than we have in the past.

We have children that are born prematurely that are living today because of equipment, drugs and knowledge, who would have not been here too many years ago. We have high spinal cord injury patients, trauma patients, that would not be alive today without the use of some sort of mechanical ventilation or other sorts of interventions.

I think we will continue to see advances and as the advances continue, we will also see an increase in the number of these technology-dependent patients. However, our support resources have not kept pace with our advances in medical technology.

I was once talking to a man who works with handicapped children and he said we are saving children, but we are saving them for what? And he is right. There is more to life than just being alive. We have to ensure that these children's needs—their emotional, their psychological and their social needs—are attached to.

At this point, we still have too many chronically ill or disabled children confined to extremely expensive institutions. We are willing to spend a quarter of a million dollars a year per child to keep them in an institution, but yet we have no mechanism for them to be cared for at home—at a fraction of the cost.

These emotional and psychological needs can only be met for the child by the family in the home setting, but here, too, these families need support. This is too much for one family to have to do alone.

In a hospital, a child is cared for by three shifts of nurses, with support of respiratory therapists, occupational therapists, and physical therapists. In the home setting, as it is now in many cases, the family is the sole provider of care.

This is a physically exhausting and demanding job. It is a 24-hour-a-day job and it is never done. And it is not to say that these families do not expect to make sacrifices. All families have sacrifices in their lives, but we are talking about care for a child that is ongoing, and a lot of times it is demeaning and it is drudgery and it is hard work.

We are not talking about running behind your child and getting physically exhausted as you watch him master riding his bike down the street. We are talking about the basic care that is required just for these children to be alive. It's not to say that these families do not find joy and pleasure in their child and in their child's achievements, because they do. Along with the hard work comes rewards—for both the families and the children.

I am here today with Ruby Gaines. Ruby's son, Marvin, as Senator Nickles said, is a 15-year-old who, last April, was popping wheelies on his bicycle, like most 15-year-olds have done at some time. Unfortunately for Marvin, he fell and hit and suffered a high spinal cord injury. The injury was so high that not only does he not have any movement or sensation below his neck, but he is also unable to breathe on his own.

He is confined to an electric wheelchair, which allows him some independence, and he is also confined to a mechanical ventilator which he requires 24 hours a day. Currently, Marvin is at home. He is cared for mainly by his family, with 2 days a week for 2 to 3 hours of outside nursing assistance. Even with this assistance it is too much for a family to do and remain intact.

These families like the Gaines need some form of respite care, which is usually not available—either because we do not have the nursing support or we have no formalized respite program.

The hospital cost for Marvin for his 8 months was $194,000, which is not at all uncommon for patients with these needs that spend that length of time in the hospital. His home costs are approximately $200 a month for supplies; nursing care, if he were to have the amount of nursing care required to help this family, would be approximately $800 a month.

For this fraction of what we are paying in hospital expenses, many of these children like Marvin could be well cared for at home. The families could have the support that they need and the children could continue to grow and develop as they should.

Marvin has been a unique adolescent. He returned to school in a wheelchair, which would be difficult to do for any adolescent. He

has gone to a new school because that was the only school that was as accessible as needed for him.

The family has done without things. The other family members have done without time that they deserve so that the family could care for Marvin.

We need to have some sort of organized funding so that these children can be cared for at home. Like someone mentioned earlier, these fragile children are oftentimes falling through the cracks, and that is the case more often than not, I am afraid.

We have programs that are being developed or that already exist, but often their existence is not known or because of their maze of personnel and paperwork are too difficult to access for many. At present there exists no coordinated program to provide care for these chronically ill children. In Marvin's case, we attempted to call different organizations for assistance and each time you called you could get a different answer. We did go to individuals for contributions for supplies and equipment we needed. Also, the VNA, which is assisting the Gaines, is donating some of their time as well.

This family and a group of individuals that I work with persevered to try to get through the maze and to find the resources that were available and get them available for Marvin. But not every family is capable of this or is even willing to try.

Some families find that it is easier to just leave their child in the hospital where it will be paid for. So, the way the system, as comp'ex as it is, and in some cases inadequate—the way the system exists today, we, in essence, penalize these families who want to remain intact and care for their children at home and to remain functional, healthy families.

Thank you for the opportunity to be here today.

The CHAIRMAN. Well, thank you.

Senator Nickles.

Senator NICKLES. Just kind of a quick question. Has the State of Oklahoma qualified—are you receiving some Medicaid reimbursements today for Marvin?

Ms. BERRY. For his equipment and supplies; the crippled children's program in the State of Oklahoma has covered most of those. But even so, as it is right now, for a family of five making $1,100 a month, their spend down is $470 that they must pay out of pocket for medical expenses. And it is impossible for a family of five to live on not much more than $600 a month.

Senator NICKLES. You mentioned a fund where they were being reimbursed. Was that under Medicaid?

Ms. BERRY. Yes.

Senator NICKLES. How much is that reimbursement per month? Do you know?

Ms. BERRY. It is covering their supplies.

Senator NICKLES. In dollar terms.

Ms. BERRY. Probably not more than $200 a month.

Senator NICKLES. Not more than $200 a month, is that right, Ruby?

Ms. GAINES. Yes.

Senator NICKLES. Now, the cost—and I saw Marvin in the hospital—you mentioned was $194,000 for, what, about 8 months?

Ms. BERRY. Yes.

Senator NICKLES. So you are running over $20,000 a month, almost $800 a day, I guess, that would be the expense. That is just a guess; $800 a day; is that close?

Ms. BERRY. Yes.

Senator NICKLES. And the family, I know, wanted him to return home, and so you went to a great deal of expense and effort and everything to get the home fixed.

Mr. Chairman, so you will know, Marvin is a quadraplegic; he has no movement below his neck. Is that correct?

Ms. BERRY. That is correct.

Senator NICKLES. And when he was in the State institution, basically, I am going to say the Government, either a combination of the State or Federal taxpayers, was picking up the expense. So they moved him from an institution that was costing in excess of $800 a day into a home environment so he could be with his family and his friends and go to school, and so on, and the reimbursement is something like, what, $200 a month?

Ms. BERRY. Correct.

Senator NICKLES. Mr. Chairman, there are some real inequities to go from $20,000 per month to less than $200 a month. I mean, I think that is something that we need to take a look at, and I will try and help you in that regard.

Ms. Berry, you also mentioned that there is another quadraplegic in Oklahoma. Have they received a waiver to date?

Ms. BERRY. No, sir.

Senator NICKLES. What is the situation? Is this an individual that is in the hospital, a quadraplegic wanting to go home and looking at the same financial situation as Marvin and Marvin's family did?

Ms. BERRY. Right.

Senator NICKLES. Oklahoma has not received the model waiver. Would that help if Oklahoma used that program?

Ms. BERRY. I think that there would be more services provided to the 50 individuals, but even that, with having to go back and renew it every 3 years—we still are lacking in a well organized program that would help these children.

The Gaines were doing better than some families because they did have insurance with her husband's work, but unfortunately some insurances have limits and his was $100,000, which spending just a few months in the hospital will quickly exhaust.

Some of these families do not even have any insurance to begin with, so there is nothing to buy the home equipment with. And the equipment that we are talking about and the supplies—those are the basic necessities for getting these kids home.

We still do not have a program that would cover devices, environmental control systems, that would enable the quadraplegic children to be more independent. These are just the basic necessities for their day-to-day survival.

Senator NICKLES. I understand that.

I might, Mr. Chairman, if you do not mind, ask the Becketts—you helped lead the fight to see if we could not get some reimbursements for home health care, I guess, instead of institutionalization.

The reimbursements that we are talking about for Marvin Gaines seem very low. Have you had better success, possibly, in your State of Iowa as far as the reimbursements are concerned.

Ms. BECKETT. Well, there are a number of States around the Nation that have been able to access various services for these children and get them reimbursed. Some States do provide some type of nursing care; some of them provide various therapies that are included, all of that reimbursable.

I know that at this point there are a number of services that can be reimbursed under Medicaid, but it is up to the States to decide which ones they wish to reimburse. For instance, I know a bill was put on the floor by Congressman Wyden the other day about respiratory therapy getting covered.

Well, when I talked to the people in the Government about it, I asked, is respiratory therapy actually covered in the States, as well as covered under home health care services? But, see, if it does say respiratory therapy, that does not mean the State has to provide respiratory therapy.

We are talking about, you know, respiratory therapists who are qualified to provide that kind of service.

Senator NICKLES. So there is a great deal of——

Ms. BECKETT. So there is a great deal of variance across the States as to what kinds of services can be reimbursed. Oklahoma is going to be different from Iowa. Iowa has a model waiver and has attempted to apply for four home- and community-based waivers, all of which were denied mainly because they could not show that there would be cost effectiveness; there would not be a limitation or a reduction of nursing care beds.

Because it was not just hospitalization children getting out of hospitals—not just institutions, but hospitals—then it is difficult to show that kind of cost-effective care. With Katie's care and with the number of cases that you have seen this morning, all of them are mainly coming out of intensive care situations where the intensive care is extremely expensive.

That is why one of the recommendations that I put forth is to examine what kinds of cost effectiveness can come out of technology-dependent children because of their dramatic increase.

If we provide services for the technology-dependent child as home health care services, those services then are going to be designed within a State to be accessed by other populations, and should be accessed by other populations. But Medicaid cannot be forced to pay for everybody who is not already a Medicaid recipient.

Not everybody is going to qualify under Medicaid, and then those services are not necessarily covered. You see, it is all very complicated and you almost have to have a game plan ahead of you for that particular State when you go to action to work on something. That is what SKIP really does. We work very closely with the States to find out what they do have provided, and then how can we turn that around to make the child accessible to those kinds of services.

Senator NICKLES. Well, I appreciate your comment. And, again, Mr. Chairman, thank you for your indulgence.

Debbie Berry and Mrs. Gaines, I again will repeat it seems to me like we have some work to do as far as the program in Oklahoma. And I think, Ms. Gaines, you have the misfortune, I guess, and Marvin has the misfortune of a terrible accident, somewhat exposing that there is a real void, I think, in coverage in the State.

My guess is it is probably not just in the State of Oklahoma; it is probably in the majority of States that need to look at this program and see if we cannot make some greater emphasis, Mr. Chairman, on home health care in lieu of the hospitalization.

I hope that we will be successful in doing that, whether it be on an individual basis or whether it be in a more comprehensive national directive.

The CHAIRMAN. Well, thank you, Senator. I appreciate your leadership on this committee.

I want to thank all four of you. I think your idea of a commission to figure out all of these inconsistencies and all of these very difficult problems may be an answer here; I am not sure.

Ms. BECKETT. I would like to just add very briefly that I went and saw a number of the people who would participate in a particular forum of this sort, both in the public and private funder sectors.

I think they have all been convinced that, yes, something has to be done, and they are all willing to at least sit down and talk. That is something more than what they were going to do several years ago. So at least we are moving in that direction.

This is not to point the finger at anybody and say, you know, this person is not doing enough or, you know, the private health insurance people are not doing enough or the public funders are not doing enough. Everybody has to work together on this.

These are our children; we all carry the responsibility. Just because it happened to me does not mean it is not going to happen to you and we have to be prepared for the future at this point. Medical technology has far surpassed what we have done to keep up with the financing of this kind of care, and these kids deserve that.

The CHAIRMAN. Well, I think you summed it up and I think anybody who looked at these beautiful children here today can understand why parents are fighting so hard for their children and why they deserve this type of help and why, really, in the final analysis it will save so much money, really, and still provide greater love and greater warmth and greater feeling of well-being to these young kids who sometimes are deprived of so much, but yet bring so much into our lives.

Ms. BECKETT. And the prognosis of these children—one of the things that you have to examine, too, is the fact that these children do so much better at home. They survive so much better.

The CHAIRMAN. Sure.

Ms. BECKETT. Katie was on a ventilator 16 to 18 hours a day when we first brought her home 3 years ago. She is hardly on a ventilator but 7 hours a day now, at the very most. And she talks, she goes to school, she participates in Brownies and day camp and everything under the Sun. That is what kids are supposed to do.

Yes, she is one of the better ones in this population, unfortunately, but it does not mean that it cannot happen. And medical technology is moving so quickly, we do not know what is left for the kids who at this point cannot walk and cannot talk.

The CHAIRMAN. I suspect 10 years from now, we are going to have even greater breakthroughs.

She has been winking at me throughout the hearing.

Ms. BECKETT. She wanted to say something. Would that be all right, Senator?

The CHAIRMAN. Sure. Katie, we would love to hear what you have to say.

Ms. KATIE BECKETT. I am glad to be home. I like my friends and going to school and going to Brownies.

[Laughter and applause.]

The CHAIRMAN. Well, thank you.

We do have statements from Senators Grassley and Kerry that we will insert into the record.

[The prepared statements of Senators Grassley and Kerry and additional material submitted for the record follow:]

STATEMENT OF SENATOR CHARLES E. GRASSLEY AT A HEARING OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES HELD JUNE 18. 1985, ON THE SUBJECT OF PEDIATRIC HOME HEALTH CARE.

THANK YOU, MR. CHAIRMAN. I WILL NOT BE ABLE TO STAY LONG THIS MORNING BECAUSE I HAVE THREE OTHER HEARINGS TO ATTEND. BUT I DO WANT TO ACKNOWLEDGE AND WELCOME TWO OF MY CONSTITUENTS, JULIE AND KATIE BECKET, WHO TOGETHER HAVE DONE A GREAT DEAL TO CALL ATTENTION TO THE PROBLEMS FACED BY MEDICALLY VULNERABLE CHILDREN WHO NEED PEDIATRIC HOME HEALTH CARE AND THEIR FAMILIES.

THE BECKETS HAD TO GO ALL THE WAY TO THE VICE-PRESIDENT AND PRESIDENT, WITH THE HELP OF THEIR CONGRESSMAN, TOM TAUKE, TO GET RESTRICTIVE MEDICAID REGULATIONS RELAXED SO THAT KATIE BECKETT COULD BE TAKEN CARE OF BY HER FAMILY AT HOME AND SO THAT THE GOVERNMENT COULD BE SAVED SOMEWHERE IN THE NEIGHBORHOOD OF $10.000 PER MONTH IN HOSPITAL CARE.

AS I UNDERSTAND IT, AS A RESULT OF HER CASE THE DEPARTMENT OF HEALTH AND HUMAN SERVICES ESTABLISHED A REVIEW BOARD FOR SUCH CASES WHICH CAME TO BE CALLED THE "KATIE BECKET REVIEW BOARD." THIS BOARD WAS ACTIVE UNTIL LATE LAST YEAR AND WAS ABLE TO HELP A NUMBER OF CHILDREN IN CIRCUMSTANCES SIMILAR TO THAT OF KATIE BECKET.

THE BECKET FAMILY IS TO BE APPLAUDED FOR THEIR DETERMINATION IN VERY DIFFICULT CIRCUMSTANCES.

THANK YOU, MR. CHAIRMAN, I HAVE NOTHING MORE.

50-222 O—85——6

STATEMENT OF SENATOR JOHN KERRY
HEARING ON HOME HEALTH CARE FOR CHRONICALLY ILL CHILDREN
COMMITTEE ON LABOR AND HUMAN RESOURCES
June 18, 1985

Today, we see the faces of courage and determination before us. They represent the possibility that there can be rational, effective health care systems that combine efficiency with personalized family and community care. Those of you who have worked so hard to demonstrate this possibility and share it with us have my profound respect and gratitude.

I am pleased that my own state of Massachusetts has recognized the importance of home health care. Massachusetts has obtained waivers to provide home and community based services for the elderly which save Medicaid approximately $70 million annually while retaining the compassion so essential to a system of medical services. I also am pleased that my State is moving to extend these waivers to children who otherwise would not be eligible for home health care under Medicaid.

We know that home health care can make dramatic differences in terms of both therapeutic value and costs. The system of waivers instituted by the Health Care Financing Administration has demonstrated this point. But this recognition is only a beginning. We now must work to eliminate the delays and inequities which flaw existing programs. We must acknowledge the existence of a new population of technology-dependent children with a new set of needs. We must find a way to transform an archaic system of covering health costs established twenty years ago into a system which effectively and efficiently meets the needs created by today's techology. And ultimately, we must look to the establishment of a fair and flexible system.

I welcome this hearing as an opportunity to learn more about the operation of home health care programs, and I commend Senator Hatch, Senator Kennedy, and other members of this Committee for keeping this issue before the public.

CRATER DISTRICT

Infant Intervention Program

2008 WAKEFIELD STREET
PETERSBURG, VIRGINIA 23805

TELEPHONE (804) 862-9940

June 17, 1985

Senator Orrin G. Hatch
Chairperson
Labor and Human Resources Committee

Dear Senator Hatch and Committee Members:

Our agency, the Infant Intervention Program receives funding from multiple sources (e.g., United Way, local tax support, fees, and third party payments, and Virginia Department of Mental Health and Mental Retardation), to provide developmental therapies to handicapped and high risk infants (age 0-2 years) who reside in our large, rural catchment area. Among the wide variety of children we see, many exhibit developmental delays secondary to extreme medical procedures which are life-saving, but at the same time inhibit interactions with the environment which are necessary for stimulation of motor, cognitive, and language development.

Examples of infants who exhibit delays due to this etiology include infants with cardiac defects, immune defficiencies, or cystic fibrosis. Children who are ventilator-assisted are also in this group. For nearly the past year, our program has been involved with a child who is now over two years old. Born prematurely, his lungs were not developed well enough to support him, and he spent most of his first fifteen months of life in the hospital. His release from the hospital was made possible only by the availabiltiy of sophisticated breathing apparatus which continues to sustain him. During the course of his struggle for life, this child was weakened and confined to the rigorous environmental standards imposed by the hospital. When we became involved with him, although we believed he had normal intellectual potential, he displayed broad delays in all areas of development. Of course, through the ventilator he was no longer in a constant battle for breath, but that very equipment and his history of life threatening emergencies had robbed him of opportunities to experience and explore the world which are so readily available to most infants. Without occupational therapy, physical therapy, speech therapy, and special education, which were provided through a team approach, we believe this child's developmental skills would not have improved as drastically as they have, and the resulting improved quality of his life may have been postponed.

Of course, "our" child is only one of thousands of children across our country whose stories sound very similar, but I believe he does exemplify the point that health maintenance alone cannot be the sole intent of home health care for children. Without the input of highly specialized pediatric therapists and educators, home-bound children, although medically stable, may unnecessarily become functionally retarded. I am extremely pleased that you and your committee are considering home health care reform, and hope that broad-based services will be recognized as a necessary core for meeting all the needs of health impaired children.

Sincerely

Joal S. Read
Program Director

Medical College of Virginia
Virginia Commonwealth University
P. O. Box 276, MCV Station
Richmond, Virginia 23298-0001
Telephone: (804) 786-9964

June 13, 1985

To Whom It May Concern:

This letter is to address the issue of the infant and child with chronic illness who requires prolonged technological support in the home. As a neonatologist currently involved in the care of high risk infants, I am more and more aware of the increasing need for home care provisions for children with chronic disease. The major types of chronic illness which produce these chronic needs, in my experience, have been: 1. chronic pulmonary disease in the form of bronchopulmonary dysplasia, 2. short bowel syndrome as a consequence of necrotizing enterocolitis, and 3. neurologic impairment based on congenital or acquired neuromuscular disorders. In regard to the child with chronic pulmonary disease, the infant may require prolonged oxygen support for months to years prior to being able to tolerate room air. These children may also require specialized care in the forms of a tracheostomy, gastrostomy or possible ventilator support. In regard to the child with short bowel syndrome, these children require specialized formulas and, on occasion, require constant feedings by a pump infusion. The child with impaired neurologic function, in particular in regard to respiratory muscular function, may require chronic ventilation at home as well as a tracheostomy and gastrostomy.

Once these types of children have manifested stability, it is important that they be allowed to proceed from the hospital to a more normal environment for future care. This is critical for the functioning of the family and for the normal developmental functioning of the child. In order to accomplish this, the infant must be stable, the family must be able to demonstrate competency in the skills necessary to care for their child, and some financial resource must be identified to provide for the continued care that is needed for this child. The first and major issue is that of stability. Obviously, if the infant is demonstrating significant fluctuations in his medical status, he cannot be managed at home. However, the majority of these infants will reach a point where they demonstrate adequate stability while still requiring technological support. The second issue is that of the competency of the family. In approximately 50 to 75% of the situations in which I have been involved, the family is competent to care for the child. This is a family who is intellectually capable of understanding the needs of the child and able to recognize the problems that their child has and can communicate by phone with the physician in regard to special problems. The family must be motivated to learn the skills that are required to care for their child and to demonstrate their proficiency in these skills prior to discharge.

However, even accomplishing this, it is often an overwhelming burden to ask the family to perform these skills on a 24 hour basis. It is crucial that they be provided with some type of support at home in terms of skilled nursing to allow them a respite.

If the family is fortunate enough to have adequate third party coverage, skilled nursing can be provided based on information from the physician, with 80% coverage in the majority of situations. Occasional policies will actually cover up to 100% of specialized care once the deductible has been met. Other insurance companies have been innovative and have instituted case management protocols in order to make their contracts more flexible to provide home care for infants who are requiring long term hospitalization. The model for this has been Aetna. In contrast to this, when dealing with Blue Cross and Blue Shield of Virginia, there is a total inflexibility in regard to altering the contract to help a family go home with a chronically ill child. This is irrespective of the savings that would be made if the child were discharged from the hospital. I feel it is crucial that insurance companies establish flexibility in regard to chronic home needs in order that these children may be discharged home. This not only saves them significant amounts of money, but also allows for the more appropriate development of the child and superior functioning of the family.

In contrast to these cases are those children who have no third party coverage and whose families may be covered under Medicaid. There is no provision for these children for extended private duty nursing care. In the case of Medicaid in the State of Virginia, the oxygen equipment or pumps would be provided, however, a cardiorespiratory monitor will not be provided regardless of the child's respiratory status. Additionally, they will not provide the adequate duration of nursing skills that are required in the home to allow the child to be discharged from the hospital setting. For this reason, these children must be kept in the hospital until they no longer require the levels of support that would necessitate home duty nursing. This has resulted in children staying in the hospital until up to two years of age, until such time as they could be weaned from their oxygen support or specialized nutritional supports. There is no alternative placement available in the State of Virginia as there are no provisions for children requiring prolonged ventilatory support. The only alternative is placement in a nursing home in another state. This, obviously, results in separation of the family and additional stress to the family as well as to the child. For this reason, we have elected to keep the children in their present hospital setting.

I feel that this issue of chronic illness in children needs to be addressed on a national level and that efforts need to be made to encourage flexibility both in the Medicaid Program, as well as in the private sector to allow these children the privilege of being cared for within their own home. In the past year, I have managed twelve infants at home on oxygen support, as well as one child who has required ventilator support in the form of continuous positive airway pressure. These have all been very successful experiences, from the standpoint of the physician, as well as for the child and the family. I am a strong advocate of home care for chronically ill children and feel that all efforts should be made to extend this privilege to children from homes without adequate third party coverage.

I would like to offer my services as a resource person or as a contact person who might be able to assist you in providing information regarding the problems in this area of chronic home care management.

Please feel free to contact me if I can be of service.

Sincerely yours,

Kathryn Kerkering

Kathryn W. Kerkering, M. D.
Assistant Professor of Pediatrics

KWK:bab

June 8, 1985
Skip, Inc. National Meeting
Senate Public Hearing
Committee on Labor & Human Resources
"Pediatric Home Care Issues"

Hugh is a 23 month old and out of those 23 month he spent 13 of them at the Medical College of Virginia either in the Neo-natal unit or the Pediatric Intensive Care unit. We made visits to the hospital everyday spending 8 to 12 hours a day and driving 62 miles to be with Hugh, to bond and do all the other things you normally do to make the development of your child normal and their growth as close to reality as possible. Our family also consist of two other boys. Brett 14 and Ryan 10. Until Hugh was 6 months old they were allowed to only see him through glass windows. — Try bonding through glass!

The strain on the family is tough but quite all striving for the same goal (getting that child home) and that keeps us going and pulling together. We seldom all ate dinner together. — We wanted to be the ones to put Hugh to bed at night. Only one of us made it to Swim Meets or Baseball games. Thank God for Grandparents and uncles and Aunts.

But and Ryan love Hugh as well as he loves them and they have become a huge part of his growth and development.

When he finally came home at age 13 months he weighed 11 lbs., ~~this~~ and was developmentally at the age of a 7 month old child. He couldn't sit unassisted, he was totally tube fed — But he was Home!

In the 10 months that he's been home not only has he learned to sit up by himself but is walking over around and through things —

He is still tube fed but is eating by mouth also. He can sign — and is talking around his trach. With the help of OT, PT, and speech at home developmentally he is right where he should be for his age — Even starting to approach towards 2's. He now weighs 17½ lbs. Except for and IV pole that holds this equipment that is rolled around behind him he is a normal 2 yr old.

Even with all the support and love from the staff at the hospital the development of these high-tech children will fall way behind unless we as parents and you as government officials do something to see that these boys and girls have every chance for a normal life, and normal life starts at HOME.

Funding for equipment, nursing, education, transportation OT, PT and speech are vital to these children.

With a chance to go home and a lot of love and patience these children really fitting in one of your pets instead of some welfare line.

Thanking you for Hugh and all the other High-Tech Kids of this great country!

For Hugh his Mom

Cindi R. Clark, MOM
1472 W. Princeton Rd
Petersburg, VA 23805

June 19

Testimony before the Virginia State Senate on 6/19/85 by Dr. John J. Mickell on children in need of chronic mechanical ventilation

My name is Dr. John J. Mickell. I am an Associate Professor of Pediatrics and Anesthesiology, and the Director of the Pediatric Intensive Care Unit at the Medical College of Virginia. I would like to speak in support of Senate Joint Resolution No. 99 to establish a joint subcommittee to study the needs of machine-dependent individuals, particularly young adults and children.

I have collected some data for my 12-bed intensive care unit for the year 1984 which is relevant to the purpose of this meeting. During 1984 this unit cared for 509 infants, children and adolescents. The average length of stay was 6.7 days. Multiplying the patient number by average length of stay one arrives at a total of 3415 patient days of care for 1984.

Seven patients required prolonged mechanical support of ventilation for chronically disabling medical conditions. These 7 patients consumed 863 or 25.3% of the total Pediatric ICU patient days. Three of the seven chronically disabled patients were Medicaid recipients. These 3 Medicaid recipients consumed 305 or 8.9% of the total Pediatric ICU patient days. The cost to Medicaid for both room and ventilator associated charges was $310,000.00, or roughly $1016.00 per patient day.

By far the most common chronic respiratory disorder that may result in a need for chronic mechanical support of ventilation occurs in premature infants. These infants may have survived the immediate newborn period, but often have an acquired lung injury known as bronchopulmonary dysplasia or BPD as a consequence of neonatal intensive care. The scarred lungs in BPD are inadequate to the work of breathing in some of these infants. Others may be able to breath well enough on their own but will require supplemental oxygen. However, with good nutrition and optimal respiratory support, all of these infants should grow new healthy lung tissue. Gradually such infants may outgrow entirely their need for mechanical support of breathing, and later their need for supplemental oxygenation. Among this group however, some may have scar tissue within their windpipe as a consequence the breathing tubes used to connect their lungs to the ventilator. Such children often must remain in the hospital still longer until they grow big enough for corrective surgery on their windpipe. During this time they must continue to have an artificial airway called a tracheostomy tube.

Infants and children with normal lung tissue may also be ventilator dependent. Some are born with or soon acquire weakness of the muscles of breathing, specifically the diaphragm and the muscles of the chest wall. Others are born with an imperfect breathing center within the brain and may breath less deeply or not at all during sleep.

Three situations currently exist which could stand in the

way of providing home care for machine-dependent or supplemental-oxygen-dependent individuals. Those are 1) if the family is indigent, 2) if a private insurance policy won't cover prolonged home-based mechanical ventilation or or supplemental oxygen delivery, or 3) if the family structure is insufficient to the task. In the latter instance home care would often still be possible if at least 16 hours/day of home nursing care could be financed.

In investigating the cost of home care for each of these Medicaid recipients receiving mechanical support of breathing in my unit it was determined that home care could be provided for 1/2 to 1/3 of the cost of hospital-based care. In one infant this would be at a savings of $13,000 per month, and in another infant at a savings of $25,000 per month.

But there are important considerations aside from the financial in this matter. First, an intensive care unit is a restrictive environment which invariably limits the psychosocial development of the pediatric-aged patient. Second, the machine-dependent individual occupies a bed which often could better be used to care for a patient with an acute life threatening illness.

In my 7 years at the Medical College of Virginia, I have seen a slow but steady increase in the demand both for prolonged mechanical support of ventilation and for prolonged delivery of supplemental oxygen for chronically disabling medical conditions.

Total ventilator dependent patient days 863/3415 = 25.3%
Medicaid recipients 305/3415 = 8.9%

Clayburn Surber #6074394 PICU Adm. 5/13/83 Medicaid
42 1984 patient days

Dennis Watts #6087198 PICU Adm. 2/20/84 BCBS
315 1984 patient days

Jeffrey Bradshaw #5650092 PICU Adm. 2/23/84 Aetna
97 1984 patient days

Hugh Cline #5646046 PICU Adm. 4/21/84 Bankers Life
80 1984 patient days

Janice Turner #5649737 PICU Adm. 6/26/84 Medicaid
189 1984 patient days

Tameka Nichols #7011991 PICU Adm. 10/19/84 Medicaid
74 1984 patient days

James Hedgepeth #5578608 PICU Adm. 10/22/84 Newport News Shipyrd
66 1984 patient days

Dear Senator,

The following is a story about a very special little boy. His name is Seth Bailey and he is my two year old son. To look at Seth now one would have no idea what he has been through in his short life, except to notice that he has a tracheostomy-a tube in his neck to help him breathe. This is also where his respirator is attached when he sleeps. Seth was born as healthy and normal as any parent could hope or pray for. At age five months he contracted asceptic meningitis and slipped into a deep coma. We were told that he would probably not regain consciousness, or if he did, that he would be a vegetable. After being in a coma for over a week, Seth gradually regained consciousness. As time went on,all of his faculties returned except the very basic drive of breathing. For the next seven months Seth remained in intensive care while doctors tried in vain to discover why he could not breathe on his own.

After Seth had been hospitalized in Johnson City, Tenn. for six weeks, his doctors sent him to Duke University Hospital in Durham, N. C. It was their feeling that, although they did not know why he could not breathe on his own, that he could be cared for at home. We were sent back to Johnson City with our son to begin an intensive care training course that would eventually allow us to take our son home. Three months later, we were able to accomplish this. At the time we brought Seth home, he was just two weeks short of his first birthday. He was on his respirator twenty-four hours a day and could not sit alone or clap his hands.

Three months later Seth was crawling, standing and walking with assistance. Three months after that he was able to breathe on his own during his waking hours. Now he is an active, "terrible two", walking or running wherever he wants to go. He has a vocabulary of about fifty words, even though he had to learn to cover his trach tube to be able to speak. He has consistently tested <u>above</u> his cognitive developmental skills.

Although Seth's illness has not been easy for our family, we consider ourselves very fortunate to have had the means to take care of him at home. My husband's private insurance has covered the bulk of Seth's hospital costs and home care costs. After having Seth in the hospital for seven months, with me staying with him most of the time and my husband and mother caring for our other son, we have been able to become a family again. His progress has been astounding to all of the professionals who have seen him.

Aside from all of the positive aspects home care has had on Seth and our family home care is much more cost efficient. While Seth was hospitalized, his hospital bills averaged $50,000.00 a month. At the peak of his respirator usage and oxygen usage, the cost was $12,000.00 per month. This includes twenty-four hour a day nursing care.

As I have stated, we are very fortunate to have adequate insurance coverage. However, due to the uncertainty of Seth's prognosis, we have no idea if this condition will continue to improve. His condition could well extend beyond the limits of our insurance coverage. I am also very concerned for the children I have seen in hospitals where we have taken Seth for treatment who cannot be taken home because their parent's insurance coverage has run out and who are ineligible under present Medicaid laws for assistance. At present, Medicaid is paying the cost of the hospitalization of these children. It seems tragic to me that these children could be cared for at one third of the cost at home and that the government is unwilling to realize this.

Mrs. David N. Bailey
107 W. 2nd St.
Big Stone Gap, VA 24219

ARTHUR KOHRMAN, M.D.

ADDITIONAL TESTIMONY

Pediatric home care is not a new idea. During my childhood in rural Ohio, care at home for the sick, and particularly for chronically sick people, was a common practice. The hospital was a resource of last resort where one went only for specific interventions. Those who died in the hospitals either had no family or were destitute. Home care is not a newly-invented concept. A great deal can and must be learned from the past in planning programs for the future.

It is important to recognize that part of the renewed interest in home care is a return from what others have described as a "technophilic honeymoon." Some of us have a belief that technology can and will provide limitless solutions to our problems. Although never stated quite so boldly, there is also the implied belief that technology might solve the ultimate challenge - death itself. The idea of forestalling death, particularly our own, is so tantalizing that our country has put an unprecedented trust in technology and in its powers to solve the timeless problems of all generations of human history.

I emphasize this point because if all we do is transfer from the hospital to the home that same uncritical view of technology we have accomplished very little in reasserting the importance of the human element into care in the home. Therefore, we must not imagine, as some have, that the homecare movement is simply a re-creation of a high-technology environment in the home. We must recognize that the move toward the home is evidence of our acceptance that technology is our servant and not our master, and that the focus of the home care movement must not be on the technology itself, but on the technology as a support for options for care which address human dignity and potential.

As part of the recognition of the limits of technology there has also risen a certain healthy skepticism. We have come to realize that those who live by

technology can also die by it. The ultimate promise of technology is not deliverance from the vagaries of life and death, but merely assistance in the journey. All concerned about home care should want to participate in helping people through that journey. In the case of the children for whom many of us care and who have their whole lives ahead of them, we want to make that journey as optimistic and developmentally successful as possible. For those of us who also care for children and adults at the ends of their lives, we want to make the journey to death as comfortable and as rational as possible.

The current interest in home care has developed in the context of several changing social attitudes that affect health care, among them suspicion of hospitals and medicine. In developed countries around the world, recent costly technological advances in medical care apparently have had only a marginal effect on prolonging average life span and reducing morbidity. These observations lead to the speculation that our tangible and emotional investment in the contemporary American medical care systems may not be yielding satisfactory benefits on a societal level.

A dominant influence in the health industry today is cost containment, but the interest in pediatric home care has not been motivated by cost-effectiveness alone. Humanitarian interests have predominated in the pursuit of new goals and opportunities for chronically ill children. Cost control has become a powerful impetus to the movement and has increased the visibility of home care programs, but the primary rationale for home care has to be kept in its appropriate perspective.

What is the nature of the "home care" movement? Home care for the chronically ill child consists of a series of interrelated initiatives to help these children to move into and stay in their homes or in to other best "least restrictive" settings; to maintain the child's medical and social stability in those settings; to redefine institutional boundaries and missions; and to focus

on the interest of the child and the family, rather than on the interests of the health professionals, the institutions, the third party payers or the vendors.

The consequences of the home care movement, if played out to the full extent, will have profound effects on hospital organizations' size and financial structure. Cherished traditional and professional roles will change as well. The redirection of significant amounts of money to non-traditional, newly emerging parts of the health care economy will affect existing reimbursement mechanisms from both the public and private sectors. Home care programs for chronically ill children will have significant economic consequences, if only because children who are considered to be seriously chronically ill, (approximately 1.2 percent of the children in the United States) currently account for 25-30 percent of all the in-patient days in pediatric hospitals in the United States. The shift of the care of those children from the in-patient setting to the home must have profound economic consequences on our institutions and our reimbursement mechanisms.

The pediatric home care field is characterized by much enthusiasm among parents, professionals, payors and vendors. Although initiative and energy have been high in the home care movement, this zeal has been, in my view, appropriately tempered by the concerns of hospital administrators, state and federal officials, planners, physicians, licensing agencies, and even some parents. Much of the concern has to do with the unknown real impact of home care on the lives of ill children and their families. Possibilities for abuse within the system clearly exist. I speak here about poor care as well as potential financial abuses. It would be foolish and short-sighted not to recognize the legitimate and real concerns about home care; we must particularly honor the questions which some parents have had about the long-term impact of caring for a very complicated, dependent child at home.

The real challenge for pediatric home care is to make sense of a vast set of

ideas and diverse motives and to encourage the best aspects of these intentions. We must question how to best approach the goal of designing and implementing programs to accommodate individual situations and maintain or improve the quality of care and life.

We have precious little evaluation or data about what the real, intangible but important effects of home care are on the growth and development of families, and of other family members. Those studies are just beginning: we must be careful not to apply uniform monolithic solutions to diverse problems without being very aware of the potential negative impacts of some of our actions and philosophies.

There are a set of what I cali ethical concerns which must be looked at intensively by those involved in making public policy. We must remember an important lesson; we all clamor to have our favorite programs embedded in legislation and regulation, but forget that that prescription often becomes proscription. The more defined a policy is, the more limited are the opportunities in its application. This is particularly important in discussing a population of children whose problems are of such an individual and idiosyncratic nature that wholesale, highly detailed prescriptive public policies may, in fact, cause more damage than good.

We must, of all things, avoid home care becoming a one-way street. I am concerned about the risk that children in home care might be refused access to the appropriate acute-care hospitals and other institutions because somebody has determined that they are now "home care" patients. We are beginning to see trickles of this concern in the hospice movement, where once someone is declared to be terminally or mortally ill, their ability to regain access to acute care facilities and resources, which might in fact ameliorate their condition or extend their lives, is becoming somewhat problematic in some settings.

Home care must never become a prescription for all children. The autonomy

of children, parents, and families must not be supplemented by one or another of our professional ideas of what is best for the child or of which ideals should be valid for the family. Constant renegotiation, reevaluation, and eagerness to search for good solutions must stand at the center of home care programs. Parents and caretakers are often understandably reluctant to voice problems or suggest change. They worry that they have failed, and hesitate to challenge what they perceive as authority. Therefore, long-term planning must include deliberate, stated opportunities for periodic renegotiation about the child's placement, under the then current circumstances of daily life and the family. It is up to those who are service providers to take the lead in facilitating and permitting these families and these children this negotiation - even if it means that the jobs of the service providers themselves are at stake. The home care market cannot become the place where the technicians, the nurses, and the therapists no longer employed in a shrinking hospital industry look to find permanent employment. The global economic and social changes in medicine cannot be solved over the beds of our children at home.

A second issue of concern is that of confidentiality, which is becoming increasingly important as comprehensive record-keeping systems become standard. Protocols for maintaining confidentiality, even in hospitals, have not been entirely successful. Professional discretion becomes all the more important as the complexity of the home care system grows. When parents and children entrust their care to others, they do not expect intimate information to be widely known and transmitted. In the more casual settings of home and community, respect for confidentiality must not become equally casual.

Just as important, we must, as a group of people with an interest in home care, whether from the commercial or from the medical or from the organizational side, begin to establish procedures that permit ingenuity, diversity, and flexibility while insuring the best outcome for each child in the family. The

clientele among chronically ill children and their families is diverse. Age, disease, race, social class, location, and access to resources are among the variables the home care movement must accommodate. The challenge to planners and innovators of programs for children is to open opportunities for children in many different circumstances without sabotaging the possibilities for other children through those efforts.

I have great concern that unless the home care movement sets standards of care, the entire field runs the risk of being ravaged by opportunists. The commercialization of child health care could become another form of institutionally-perpetrated child abuse. We must be ready to identify such abusers and to take action to prevent their entry into this field. While home care seems to some to represent a potential for revenue production, the cost of making that money in human terms could be disastrous. If the home care movement for children becomes the captive of commercial interests whose concerns are profit-making at the expense of humanistic goals, it stands to lose much of the progress which it has already achieved.

There are several critical challenges to what I call the home care industry. It is, in fact, a burgeoning industry, and recognition of this fact forces us to focus on the commercial side of the home care movement. It is useful to look at home care as an industry for a couple of reasons. First, because there are some valuable lessons to be learned from well-run and regulated industries; and second, because it is important to look at the ways in which home care deviates from a standard industrial or market model. In many ways the traditional concepts of market economics are <u>not</u> applicable to home care. A standard market analysis implies two criteria which this industry does not meet. One is saturation - that there will ultimately be a maximum demand for care within which different providers can compete. However, home care shares with medicine the anomalous position of being one of the few industries in which the supply creates

demand, instead of the reverse, the case in most other standard markets. A standard market analysis also demands an informed purchaser, who can make critical decisions among a variety of offerors in the market place. Here, the home care industry is again distinctive. Parents do not know what is best for their child instinctively, but they can become extremely well-informed in a very rapid fashion. However, they do not start with the ability to know what their child needs. It really takes an act of heroism, and a certain amount of risk-taking, even to try to crack the veil of complexity around which medicine and all its attentive professions surround themselves. Parents do not natively know how to make these complex choices.

Moreover, even though we talk about a market place in which there are many offerors, in many situations there is really only one vendor available. And as long as there is only one vendor available, then market forces do not apply. Parents who live in isolated areas or areas where vendors do not care to operate (such as the inner city or rural areas) are often at the mercy of the sole available vendor.

We have to remember that the purpose of the home care industry should be to transfer responsibility to the family as the caregivers of the patient. A central part of our professional role is to serve as teachers, as well as caregivers. We must not deliberately or subconsciously neglect our role as teachers, in order to prolong our role as caregivers to our own economic advantage. Such behaviors can only lead to more restrictive and stringent legislation and regulation from federal and state sources.

The industry must itself find ways of setting standards and policing them. By setting its own standards it will avoid the inevitable chain of events that will lead to restrictive, inflexible and inappropriate regulation. There must be avoidance of unnecessary care which drives up the cost of care. The industry and medical profession must control costs and keep quality high. We need to look at

the cost per case, and not per diem or hourly costs. In Illinois, we have experienced a 75 percent rise in the 24-hour home care cost between 1979 and 1984. Nursing care which cost $8,000 per month in 1979 is now costing $14,000 per month. There are differences of 200-300 percent in competitive bids in durable medical equipment for the same problem and in the same community. Some is due to inflation, but most is due to a shift to home health care agencies instead of private duty nurses where the large number of hours, requested over a long period of time, are being charged at the same per diem and hourly rate as if they were short-term hourly cases. If this continues it will clearly strangle the industry and our good intentions by raising the cost of home care to those of hospital care.

Imagine the uninformed parent who sits at the mercy of a single vendor who knows that a given piece of equipment is required for the safety or life of their child. The parent is hardly in a position to discriminate among or to make any complaints about the single vendor. Yet, those of us who look over our whole systems and see that same vendor, can make comparisons. We have seen in two different cities in the same state as much as 100 percent difference in charges for the same piece of equipment. I am sorry to say that these examples are not limited to fly-by-night operations; some of the biggest national names in durable medical equipment and in home health service agencies participate in what I think are unconscionable variations in pricing.

Another concern I have is that third-party payment will drive up the cost of care. One of the big boasts of the home care agencies is "we'll take care of the paperwork." They will bill Medicaid, Medicare, or private insurance; if I were a parent I would leap at the opportunity to get out from underneath the burden of that paper chase. However, this service to the parent is often accompanied by "What do you care about the cost when the insurance company or the State is paying anyway?" One of the things that we must do is to educate the parents to

recognize that they retain accountability and knowledge of those costs and charges that are being transmitted to the third-party payors in the name of their child. The governmental agencies which have control over their disbursements often are unwilling to question the charges because they find themselves in the same position as the parent when there is a sole vendor. The industry itself must take responsibility for some control.

The industry must become child, patient and family-oriented, not third-party payer oriented. One of the reasons the hospital industry is in trouble today is because most patients have not, in recent American history, participated in the transfer of funds required for their care. They have neither participated in nor exerted control over what is done or what is charged in their name to payors. We cannot allow this situation to develop in the home health care setting.

To summarize: the more pediatric home care that is available, the better off all of us are going to be. We would badly serve and our children would be badly served, if we end up in a situation in which the vendors, the payors, the providers, and the parents are in a stand-off or in conflict. We must look toward consortial and collaborative arrangements to avoid that kind of an adversarial confrontation. In my view, the industry must move rapidly to set standards, to establish internal peer review mechanisms, and to make quality assurance a part of their care from the very outset of each child's program. The industry should set aside some portion of potential profit for evaluation of home care initiatives and programs.

The industry should participate with manufacturers in research and development, particularly in the development of areas of low-technology solutions for problems of children at home with chronic illness and disability. The development of simpler and more reliable equipment should become one of the challenges to the home care movement. Patients require better means by which to control their environments, and manufacturers and vendors might well collaborate

with sources in government to develop some solutions for these problems. A basic issue is finding the necessary venture capital to develop equipment and support services for a low-incidence population in our industrialized society where potential profit is the major incentive for corporate research and development. The issue might best be addressed by consortial efforts between vendors, manufacturers, and the federal government. This might be the place for a Federal initiative in providing capital, as in the "Orphan Drug" Act.

If we do not take these positive steps, serious questions will be raised about the quality of home care, costs will increase, and abuses will flourish. Adversarial rather than cooperative relationships will develop, and we shall witness the deterioration of care and, ultimately, deterioration of this very important concept. On the other hand, if the industry - and all of us who are part of this industry - take responsibility, and if the initiatives are not from any one sector but from all the sectors, - providers, payors, clients, parents, vendors - then we will succeed in what we have all set out to do. We will show that home care is an important way to care for chronically ill children. It is more humane and serves to keep families together. We will then benefit from American ingenuity, through the kind of collaboration between private and public sectors that characterizes the American economy and American health care at its very best.

HOME CARE FOR CHILDREN WITH SERIOUS HANDICAPPING CONDITIONS

A Report on a Conference Sponsored by the Association for the Care of Children's Health and the Division of Maternal and Child Health, Public Health Service, U.S. Department of Health and Human Services.

HOME CARE FOR CHILDREN WITH SERIOUS HANDICAPPING CONDITIONS

A Report on a Conference Held May 27, 1984
Houston, Texas

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Pediatric Home Care: A Ten-Point Agenda for the Future

Arthur Kohrman, M.D.

Pediatric home care is not a new idea. During my own childhood in rural Ohio, care at home for sick (and particularly chronically sick) people was a common practice. The hospital was the resource of last resort, where one went only for specific interventions: those who died in a hospital either had no family or were destitute. With the current wave of thought-provoking approaches to pediatric home care, we must be humble enough to realize that home care is not a newly-invented concept. A great deal can be learned from the past in planning programs for the future.

Renewed Interest in Pediatric Home Care

The present renewed interest in home care is, in part, a return from what might be described as a technophilic honeymoon. As Ruth Stein has reminded us, Americans have had a love affair with technology, founded on the belief that technology can provide solutions to limitless problems. Though never stated quite so boldly, there is also the implied hope that technology might solve the ultimate challenge—death itself. The idea of forestalling death, particularly our own, is so tantalizing that our country has placed unprecedented trust in technology and in its powers to solve some of the problems that have existed through all generations of recorded history.

But, a very healthy skepticism concerning the limits and the risks of technologic dependence is also now apparent. We have come to realize that those who live by technology can also die by it. The ultimate promise of technology is *not* deliverance from the eternal verities of life and death, but merely assistance in the journey.

Current interest in home care has developed in the context of several social attitudes that affect health care—among them a (perhaps healthy) skepticism of hospitals and medicine. In developed countries around the world, costly technological advances in medical care have had only a marginal effect on prolonging aggregate life span and in reducing morbidity. These observations lead to speculation that our tangible and emotional investment in the medical care system may not be yielding satisfactory benefits.

The social climate, in fact, endorses increasing suspicion of professionals and professionalism, and greater scrutiny of motivation and incentives, with doctors serving as the most visible targets of mistrust. As society begins to look closely at the imperatives of professional guilds, organizations, and institutions, the suspicion arises more and more frequently that other interests offset those of the patient. Both the social en-

dorsement of individualism and the political movement toward local control over local activity are each reflections of changing social priorities: we are publicly interested in the empowering of individuals, while cautious of institutions that minimize individual values. These trends, among others, provide the social underpinnings of the current home care movement.

Although cost-containment is a dominant influence in the health industry today, interest in pediatric home care has not been motivated by cost-effectiveness alone. Humanitarian interests have predominated the pursuit of new goals for chronically ill children. Cost control has now become a powerful additional impetus to the movement, and has increased the visibility of home care programs, but the primary rationale for home care must be kept in appropriate perspective.

Definition of Home Care

What is home care for the chronically ill child? The broad definition that has been adopted in Illinois is derived from the language of P.L. 94-142, The Education for All Handicapped Children Act, which insists upon placement in the "least restrictive environment for the child and the family." "Home care" refers to the effort to place the child in a least restrictive environment—that is, where he or she can best develop while receiving direct care from adequately supported and supportive caretakers. A "least restrictive" setting may also be cost-effective: this sequence of priorities must be retained in the basic definition of home care.

The movement toward home care for the chronically ill child consists of a series of initiatives: to help these children move to their homes or to another "best" setting; to maintain the child's medical and social stability in this setting; to redefine institutional boundaries and missions; and to focus on the interests of the child's family rather than on the interests of health professionals, institutions, or third party payors. The consequences of this movement will have profound effects on hospital organization, size, and financial structure. Cherished and traditional professional roles will change as well. A redirection of significant amounts of money to non-traditional, newly-evolving sectors of the health care economy will affect existing reimbursement mechanisms, both public and private. Home care programs for chronically ill children will have significant economic consequences, if only because children considered to be chronically ill currently account for more than 40 percent of all the inpatient days in pediatric hospitals in the United States.

The pediatric home care field is characterized by a burgeoning enthusiasm among parents, professionals, payors, and vendors. However diverse these sources, their common interests and collective expertise are far more powerful than their separate individual influences on health care programs. Although initiative and energy have been high in the home care movement, this zeal has been tempered by the concerns of hospital administrators, state and federal officials, planners, physicians, licensing agencies, and by some parents. Much of this concern has to do with the unknown real impact of home care on the life of the ill children and their families. The possibilities for abuse within the programs clearly exist: both abuses in care as well as fiscal abuse. Such concerns constitute some of the most significant barriers in the implementation of home care programs.

Future Agenda for Pediatric Home Care

The real challenge for pediatric home care is to make sense of a vast set of ideals and to encourage the best aspects of these intentions, in order to carry programs into the future with greater certainty. In other words, we must question how to best approach the goal of designing and implementing programs that accommodate individual situations, and maintain, or even improve, the quality of care and of life. To help attain these goals, I suggest the follow-

ing ten-point future agenda for pediatric home care.

1. Examine and re-examine professional roles, attitudes, and pressures.

"We have met the enemy and he is us," to quote our friend, Pogo.

Not only physicians but all health professionals are threatened and perplexed by the new alternatives in health care delivery. If a change in orientation within the health care system is to occur, existing professions and guilds must first be examined with regard to their willingness to adopt.

The present political and economic climate of hospital care represents a marked difference from previous times when the physician had the undisputed option to perform or order, on behalf of the patient, services which in themselves were not necessarily remunerative or which required a great deal more time and effort than was justified by the income they produced.

As the mandate for cost-conscious practice grows, and as re-evaluation of relationships between institutions, families of chronically ill children, and physicians continues, the threat to the economic and organizational structures of many institutions will also grow. Because very real financial and organizational pressures influence those who control the present systems, effective plans for change must acknowledge the economic and organizational imperatives for current operations and practices.

Re-examination of the health professional's role will involve new definitions of success and failure. As health care givers, we have a conceptual view of the world that tells us to cure, to heal. Inevitably children with long-term illnesses, who neither die nor get better from our efforts, are viewed as failures, perhaps to be hidden in shame. Attitudes toward the care of the patient who requires treatment but cannot be cured present difficult personal and professional issues, which educational programs could do much to address.

Physicians, and others in the health services fields under their highly visible leadership, carry some other professionally reinforced attitudes that bear consideration. The medical profession is by definition paternalistic; we live in a society which expects medical caregivers to assume paternalistic roles. Returning power to patients is therefore not only threatening, but also unfamiliar. Permitting care at home symbolizes a relinquishing of control to the patient. Home care thus represents a transfer of authority which is difficult for many to accept, not only because of a desire for omnipotence, but also simply because of fear of unknown or unfamiliar problems or outcomes. Medical professionals worry about responsibility and are reluctant to divide or transfer that responsibility fearing that loss of continuity and control is an abdication.

We must acknowledge and teach that the physician really controls very little of a patient's life. As individuals, as well as members of interdisciplinary teams, we can only change the pattern of health care if we understand the relationship between the help we seek to offer and the control we are inclined to retain.

2. Re-examine institutional roles and assumptions.

The distribution of functions in institutions must change, if the locus of care is to be moved to the home, the family, and the community. The concept of transitional care, for example, has features that, while unfamiliar within standard models of practice, are uniquely geared to the movement of children into less restrictive placements. Transitional care *is* cost-effective, but more importantly it provides a fundamentally different environment than that of the acute care hospital. This sort of flexibility in traditional boundaries between established institutional practices must grow with the home care movement. To create a set of multi-tiered care systems, services designed around the real lives of a chronically ill pediatric population must be developed. Such systems ideally will be stratified, not

only by cost, but also by capability to meet the needs of aggregate groups of patients. These tiered systems might include acute care, transitional care, and community hospitals, as well as skilled nursing facilities and "halfway houses." A commitment to provisions for respite care is of central importance.

A simple philosophic orientation must be at the center of all institutional efforts to support home care: chronic disease practice must be guided by the interests of children and their caretakers, rather than by the needs of hospitals, nursing offices, boards of trustees, medical staffs, departments of social work, or other institutional groups.

3. Examine and define the unit for pediatric home care.

Before acknowledging the "family" as the basic unit where home care should occur, we must look at what "family" means in America today. Perhaps no appropriate words exist to indicate the diversity of arrangements characterizing what is subserved under the term "family." The much-quoted ideal family with 2.3 children, a split-level house, and a two-car garage surely is not the norm. The one-parent family is not an aberration. Twenty percent of all American children grow up in one-parent families; the number approaches 80 percent in inner city neighborhoods, and over 50 percent in some wealthy suburban communities. The minimal unit of care for a chronically ill child has been neither adequately defined nor investigated.

Perhaps most of us accept the tenet that "for a chronically ill child, as for all children, there is no substitute for the one person who cares." Results of more systematic research into the nature of family support structures and the nature of family interactions should help to assure that the child, once given adequate medical care and community support, will achieve the best possible developmental outcome. However, we know too little about family members as individuals and about families as systems. Although families often have remarkably effective ways of functioning, in many instances we are at a loss to explain why certain family systems work while others fail. The nature of the family calls for systematic investigation and dissemination of this information to health professionals. Just as attitudes toward professional roles and institutional roles affect medical practices, so also are we influenced by conventional wisdom and lore, for example, about how families of the poor operate and how families of the well-to-do operate. Culturally-held notions about the capabilities and deficits of families deserve objective re-examination and research.

The family caring for the child at home assumes the relatively untested role of case manager. In many circumstances, the possibility for family independence and smooth operation in the patient's behalf can only be achieved when the family functions in a central coordinating role. However almost no research exists on the methods and consequences of training the family to assume these responsibilities, nor on the consequences of the ultimate losses of future opportunity for the entire family. Many parents would have an entirely different vision of their lives were their child not handicapped. As we introduce new roles, responsibilities, and relationships into these parents' lives, we must also develop a new set of understandings about the effects of these changes on families.

Finally, the social and emotional growth of children themselves remains to be studied. Children with handicaps themselves might benefit greatly from direct clinical assistance with orientation toward their disabilities. The aim of a project at La Rabida Children's Hospital, for example, is to investigate the potential of handicapped children for learning self-advocacy skills. Once old enough to use the telephone and to move around, the children are trained how to use help from others, and how to be responsible for their own advocacy. An enormous field for investigation lies in the possibilities which arise from empowering these children, and fostering the sense of

competence so important in the growth of all children.

4. Set standards for care that permit ingenuity, diversity, and flexibility, while ensuring the best possible outcome for each child in the family.

Whenever global solutions are sought, the danger emerges of sequestering and suppressing the opportunities of another whole population for whom that goal is not applicable. The clientele among chronically ill children and their families is diverse: age, disease, race, color, social class, location, and access to resources are among the variables that the home care movement must accommodate. The challenge to planners and innovators of programs for these children is to open opportunities for children in many different circumstances without sabotaging the possibilities for other children through these efforts.

Unless the home care movement sets standards of care, the entire field may be ravaged by entrepreneurial opportunists. The trivialization and commercialization of child health care is a form of institutionally-perpetrated child abuse and assault. As professionals, we must be vigilant; to be ready to identify such abuse and to take action when our values for children are thwarted by opportunistic interests. Home care represents a potential for revenue production; the cost of making that money in human terms could be disastrous. If the home care movement in pediatrics becomes heavily involved with commercial interests whose concerns are profit-making at the expense of humanistic goals, it stands to lose much of the progress which it has already so proudly achieved.

5. Improve and simplify technology.

The development of better, simpler, more reliable equipment should be another hallmark of the home care movement. Patients require better means to control their environments. Manufacturers and vendors well might collaborate with sources of government help to develop technologic solutions. The economic rewards to a manufacturer willing to invest venture capital are not likely to be great.[1]

Obtaining capital to develop equipment and support services for a low incidence population in an industrialized society, where profit is the incentive of corporate research and development, is one of the major issues that might be best addressed by consortia of private and public sector representatives.

The problem of equipment is again related to social attitudes. Physicians have deemed technology powerful. In our culture we are frankly disdainful of "low tech" solutions when "high tech" alternatives exist. Nonetheless, "low tech" solutions familiar to patients, their parents, grandfathers, and neighbors should become a more significant part of our resources.

Liability consciousness plays a role in influencing professionals' attitudes toward equipment. If care of patients is to be transferred to a machine, the machine must certainly be of state-of-the-art quality. However, consciousness of product liability in this country has become counter-productive: vendors and manufacturers refuse to service machines which have been altered from their original specifications or are used in unorthodox ways. Consequently, patients are constrained to use machines that might not be able to be repaired or serviced. The issue of product liability, in both economic and legal terms, has crucial ramifications; its solution may require assistance from state or federal governments in negotiating safe, rational solutions.

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[1] A recent report for the U.S. Congress Office of Technology Assessment discusses this issue exhaustively. *Technology and Handicapped People*, Washington, U.S. Govt. Printing Office, 1982 (L.C. 82-600546)

6. Work to form regional consortia of public, private, university, and commercial sectors.

Development of trust amongst providers, payors, client groups, regulators, and educators is crucial to pediatric home care. Liaisons between the medical and educational communities are often deficient, even though they serve the very same children and have similar goals. The clear federal mandate for cooperation among educators and health professionals has not received a response worthy of the great potential for far more powerful, effective programs for children. Close rapport with teacher training programs could begin to ameliorate the deficiency in education of the educators, which rarely includes information on childhood illness, especially chronic illness, and its effects on children and families.

Regional consortia may become the basis from which creative collaborations among broader segments of the community can occur. Effective regional consortia can move beyond traditional institutional roles and professional relationships to ensure continuity for our patients between the hospital and the home and into the community. An effective regionally-based network (perhaps the term "cobweb" better typifies the necessary sticky, cohesive quality) can oversee follow-up and assessment activities as well as assume centralization of information about patients. Another role for consortia is to ensure continuity of record-keeping, and thereby provide some basis for evaluation of mutual efforts. The consortium can bring concerted pressure on state and federal agencies, especially regulatory agencies, with a strength that individual members alone cannot match. Regional and local consortia also can have important effects on cost control. By enlarging the group of people who are involved, a consortium can exert power in the market place and can influence forces of market economics.

An example of the increased effectiveness of consortium efforts exists in Illinois. The Children's Home Health Network of Illinois. One of the aims of the consortium is to develop a multi-tiered system for the ventilator-dependent child that includes skilled care options for children who cannot live at home. The three good pediatric skilled nursing facilities interested in taking care of ventilator-dependent patients cannot offer services to these children at the reimbursement rates currently offered by the public assistance system. The Children's Home Health Network, as the consortium, is now attempting to negotiate on their behalf with the public aid agencies in Illinois with force that none of the three institutions alone could duplicate. The political power that can be gained with a regional consortium can be directed to achieve a range of goals that may be unthinkable on a smaller scale.

7. Form coalitions between patients and their parents or caretakers and professionals.

The best way, albeit somewhat unfamiliar and even provocative, to effect enforcement of standards in home care is to empower the formal and informal caretakers of the child in order to assess the effectiveness of efforts on the child's behalf. To perform in this role comfortably and competently, parents and caretakers must be extremely well-prepared and informed. As providers, it is our task to prepare parents for this enormous responsibility. We must also learn to listen to parents; they have the "front line" knowledge of the intricacies of the child's daily program. In sum, parents and professionals must become each other's educators. Coalitions between parents and the medical establishment, both formal and informal, are extremely important in providing a core of continuity and of credibility in enforcement of standards in the home care system. This coalition between parents and professional should be used to keep costs low and to maintain quality. If parents and professionals are to communicate personally and publicly, they require expertly planned

forums for mutual exchange of ideas and education for directed political activity.

8. Recognize the importance of political agendas.

Particular consideration should be given to interaction between the pediatric home care movement and state and federal governments. The political process is slow and unpredictable; it demands incredible tenacity and carefully pursued lobbying efforts. However, only through political action will financial and bureaucratic barriers be broken. The political process is also a key in the home care movement as the essential determinant of the regulatory environment.

The place of the political process in affecting the organization of health care systems is undeniable. Chronically ill children deserve advocacy: they are a very vulnerable population, there are not so many of them, they cost a lot, and many are poor—within our society they have many strikes against them. One of the basic priorities for all programs for children, including the home care movement, should be to help create a voice on behalf of children within the political system.

9. Consider the ethical implications of home care.

The exciting new options created for chronically ill children must be applied flexibly. Home care must never become a prescription for all children. The autonomy of children, parents, and families must not be supplemented by narrow ideas of what "is best for the child" or what might serve ideals not valid for the family. Renegotiation, re-evaluation, and eagerness to search for good solutions should stand as central components of home care efforts. Parents and caretakers are often understandably reluctant to voice problems or suggest change. They worry that they have failed as caregivers and hesitate to challenge what they perceive as authority. Therefore, the philosophy of long-term planning must include deliberate opportunities for periodic renegotiation about the child's placement and the current circumstances of daily life in the family.

Confidentiality emerges as an increasingly important ethical issue, as comprehensive record-keeping systems become more evident. Protocols for maintaining confidentiality even in hospitals have not been entirely successful. Professional discretion becomes all the more important as the complexity of the home care system grows. When parents and children entrust their care to others, they do not expect intimate information to be known and transmitted. In the more casual setting of home and community, respect for confidentiality must not become equally casual.

Respect for cultural diversity is another issue that involves values. Each of us has a particular window of bias based upon our own origins and socialization. Cultural variations open up new possibilities as well as impose restrictions. The traditional medical establishment lacks a broad base of information about different cultures, and ways of listening and understanding are often deficient. When we ask how families from diverse cultures and neighborhoods arrange for the care of their chronically ill children at home, the answers are often surprising. Conventional wisdom does not always apply.

10. Evaluate all we do.

Our society will be forced to make some very important decisions about allocations of resources in the future. To do so wisely will require prospective and retrospective evaluations of present and future programs.

Zeal, one of the greatest assets in the home care movement, is also one of the greatest risks. The kind of enthusiasm which brings home care programs into fruition also carries the risk of impeding formation of critical judgments. Zeal is absolutely necessary, but not sufficient; testimonials are not data, and data are essential.

The attitudes and expectations of parents for their children are the real substance of our professional success—it is

these hopes and dreams that we must understand and enlarge, in order to create new opportunities for the chronically ill child. Because hopes for the future can only be launched in the context of families' real capabilities and interests, the professional imperative to respect the family's values and practices becomes a key component of the home care movement.

In sum, changes in future medical programs will be based on beliefs as to the best outcomes for children and their caretakers. Interest in cost-effective solutions for chronic pediatric populations has been a noisy element among the various sources of enthusiasm to find new opportunities for children, but certainly has not been the most important or significant part of changing priorities. Rather, the focus on the real lives of children and their families, and the effort to enhance the independent pursuit of activity in the context of family and community are the outstanding progressive hallmarks of the contemporary home care movement. These humanitarian ideals are strong enough to sustain the home care movement against entrepreneurial counter-interests; these ideals are strong enough to motivate health care providers from all disciplines to pursue research that will lead to better clinical service. And perhaps most important, the orientation toward the needs of children and families, away from institutional and organizational priorities, has potential to affect a great variety of future health and human service programs.

June 12, 1985

Dear Senator Hatch,

I would like to tell you of my experience with Home Health Care. My 13 year old son was hit by a car while riding his bike one year ago. He sustained a a very serious head injury in the accident and was comatose for 2 months. After 8 weeks in the hospital he was medically stable but still unable to walk, talk, sit or even swallow. My husband and I were spending 12 hours a day at the hospital trying to help our son in every way we could, but we also had 4 other children at home

who needed our attention. It was suggested that if we could make the appropriate arrangements we could take our son home. This included a home care nurse, a speech therapist, a physical therapist and an occupational therapist. All of these arrangements were made and we were able to take him home. From that time his progress has increased steadily. Being at home with his family and in familiar surroundings helped him immeasurably. After 2 months at home he was well enough to travel to the clinic for his therapy. In another 5 months he was able to return to school part time.

It has been an extremely difficult

year and our struggle is far from over; but, our son was hurt June 13, 1984 and on June 13, 1985 he will be with his friends at Boy Scout Camp. He can walk, run, play soccer and ride a bike. His speech is improving and he can read, write and do math. All of this has come about with a great deal of effort, but it is happening. I truly feel the first giant step toward his recovery, after his life was no longer in danger, was our ability to bring him home and make him a part of our family again. This would not have been possible without Home Health Care.

Our whole family will be eternally grateful to the wonderful people who have helped us get our wonderful son back and the Home Health Care people have been a big part of that team.

Thank you for considering the importance of this service.

A Thankful Mother

SKIP, INC.
SICK KIDS (NEED) INVOLVED PEOPLE
NATIONAL HEADQUARTERS
216 NEWPORT DRIVE
SEVERNA PARK, MARYLAND 21146
301-647-0164

Karen Shannon, founder and national executive director of Sick Kids need Involved People (SKIP), with her daughter Erin, a ventilator patient.

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The Honorable Orrin G. Hatch
Chairman, Committee on Labor
and Human Resources
United States Senate
Washington,D.C.

Dear Senator Hatch:

I am pleased to see your continued commitment and support of the children and their families across our country who suffer from catastrophic illness with a dependency on medical technology.

As I demonstrated by my testimony for the hearing on "Home Care for Chronicaly Ill Children" August 1983, I have an on-going involvement in this new movement as a parent of a technology dependent child, ERIN 5 years old, born with a rare respiratory disease. Erin is at risk of respiratory collapse because of immature development of cartilage in her lungs. Erin requires 12 hours a night of positive pressure mechanical ventilation to keep her lungs open. I also am the Founder and National Executive Director of the organization,SKIP (Sick Kids [need] Involved People).

SKIP grew out of my personal experiences, triumphs and tribulations of having Erin,a medically fragile child. As a pioneer in this movement, I continue each day in not only confronting, the continuing road blocks placed in front of me as a parent striving to keep her daughter, ERIN, home but in assisting thousands(1000's) of families and their medical teams across the country being faced with the same challenges day after day: appropriate funding, quality care and society's acceptance.

The opportunity to identify these issues and increase public awareness and community understanding of the real challenges facing the thousands(1000's) of families is truly a milestone in the continued efforts to insure that the option for Pediatric Specialized Home Care will continue for all the children of our country.

Thank you for your continued support and backing.

Sincerely,

Karen A. Shannon
Founder/National Executive Director

SKIP'S NATIONAL ISSUES

The national issues facing the technology dependent population is not unlike those faced by other health impaired populations. Main issues include identifying funding, disseminating of program information, addressing educational and social needs of the child and family, and providing for quality assurance, and the education of both professionals and the public on the issues and needs of these special home intensive care children.

-Identifying Funding Programs:
The need for appropriate individualized funding policies and procedures for handling financial support and assistance to these families is critical, both in private and public sectors. There is a need to recognize that some families can cope with fairly minimal supports, while others may require high levels of support and assistance. Flexible funding is vital because the family situation changes over time, and home care arrangments need to adapt accordingly.

-Meeting the Educational, Developmental and Social Needs of the Child and Family:
The technology assisted child places unique, new demands on our established educational and social systems. It is important that we not neglect preparing and integrating him/her into our society. Provisions for educating this child must be established both in public and special education settings. Peer acceptance must be fostered through understanding as well as exposure. Encouragement through educational and support systems will one day allow for the self-sufficiency of the technology-dependent children.

-Disseminating Information:
There is a great number of existing, well established programs promoting maximum family growth for specialized care in small localized areas of the nation. A system must be established to collect and distribute information throughout the nation on how different programs/resources were planned, developed and how they now operate. The system must share information on available treatment centers and costs to families, health care professionals, medical insurance carriers, regulatory agencies, and non-profit organizations - ultimately linking all systems in order for specialized health care to survive through coordinated management on all levels.

-Quality Assurance:
The development of standards of care, must be established that are flexible, diverse and individualized for each child. Avenues for monitoring are needed to assure that the services and the products are being delivered in the community are of the highest caliber possible.

-Education of Professionals and the General Public:
It is vital that professionals in all sectors of society,including medical, business, law, financial, education, social, religious are made aware of this growing trend to home care. Professionals must incorporate in their educational curriculum specialized home health care management and the development of new skills that are needed to service home health care recipients. The general public needs to become aware of the needs and issues facing home health care families. This awareness will hopefully develop the volunteer system for assistance and promote legislation to make life smoother for these families involved in specialized home care.

LABOR AND HUMAN RESOURCE COMMITTEE PUBLIC HEARING

Home Health Care Reform/Pediatric Home Care Issues
Testimony of Karen A.Shannon -Parent-National Executive Director
Founder of SKIP(Sick Kids [need] Involved People),Inc.
Pamela N. Bennett, RN, BSN
Vice President SKIP, INC. National

Ten million children in the United States are chronically ill; one million of these children suffer from severe chronic illness requiring frequent hospitilization and medical support. Today we will talk specifically about chronically ill children, who are technology dependent. These children received superb,state of the art medical care after a premature birth, severe medical illness or catastrophic accident and survived. The Technology-Dependent child however will retain a daily dependence on the medical technology which gave him life respirators ,oxygen, tracheostomy, tubes, gastrostomy tubes, catheters, etc.

Hospital ICU's or one of the very few specialized pediatric long term care facilities have been the only "home" for these children. A new and growing option has been he care of this complex medically fragile child in his normal environment -THE HOME. SKIP(Sick Kids [need] Involved People) is involved at all levels in the pediatric home care movement, attempting to pragmatically assist families, to educate public policy-makers and legislatures related to these children and to impact on society's attitudes and knowledge about Technology-Dependent children. SKIP is composed of every facet of in-hospital and community supports, working together on this complex issue.

There are, we feel, 3 major categories of needs that must be addressed:

1. FINANCIAL
2. QUALITY ASSURANCE
3. COMMITMENT

I. Financial

Hospitalization costs represent the largest proportion of this child's medical expenditures. Though the severe chronically ill compose only 2% of the child population in the U.S., this 2% uses 60% of the children's in-patient hospital dollars each year. How might these astronomical hospitilization costs be reduced without massive reform in our health care system?

Caring for these children at home rather than in the hospital represents a reduction in hospital costs by 2/3 (see chart on cost effectiveness of home care). Average monthly costs for home care range from $6,000-12,000.00 compared with $6,000-12,000.00/a week in the hospital. Yet the primary deterrent to home care is monetary.

The broad range of services needed for the child to thrive at home are available, yet typically private insurance or Medicaid will cover inpatient hospital and diagnostic testing only. As soon as the child is at home the financial support is not only decreased but the range of provided services is narrowed. This effectively excludes many families from even attempting home care. Uninsured middle income families have no clear mechanism for financial support of their child. The child must be maintained in a hospital at a greatly higher cost to be paid for with public funds.

Families are often financially depleted by extraneous non-medical costs alone, such as transportation to physician, hospital, or pharmacy, time away from work for care, career immobility because a change in insurance company may result in a change or drop in coverage.

It is incumbent upon the government to adapt flexible, individualized financial support for the families of Technology-Dependent children. Support for the families of Technology-Dependent children which will allow them to live in the more cost effective setting--THE HOME.

II. QUALITY CARE

Though cost containment is an important concern in pediatric home care, the decision to attempt home care must be based not on cost but on the quality and value of that child's life. Dr.C.E.Koop embraced our philosophy in his speech at the Surgeon General's Workshop on Children with Handicaps and Their Families,,,,,,,,,December 1982,,,when he said "There is no substitute for a loving caring family" for these children. My daughter--Erin astonished doctors when she taught herself to speak--for Erin learned to talk because she had something to say and some one to say it to--- and a family to be part of it. The second issue of importance is the assurance of quality care for each child.

Standards must be established that are flexible, diverse and individualized for each child. Standards that will maximize each child's existence. The urgency of this can not be overstated. Home care is a new frontier with potentially lucrative financial and commercial gain to service providers. The risk of abuse if standards are not developed is great and the harm to the children and their families potentially devastating.

Quality care in the home necessitates caregivers helping parents on a daily basis. Evaluation guidelines must be developed to assess the level of care and nursing needs of each child. Some of these children who are stable can effectively utilize nursing aides or trained family or community helpers. Other children who have rare poorly understood disorders with unpredictable outcomes or medically unstable children require the skilled care of RNs. Often the medical machinery in the home has

untested long term sequelae with pediatric patients. Assessment of subtle, sometimes unrelated clinical signs and symptoms clearly is in the realm of nursing expertise.

It has been posited by some that if parents can learn to care for their medically fragile child, at home,then other lay people could too. For the medically stable or less complex child this is certainly true and should be enthusiastically promoted. For the more complex, fragile child however this is not a wise arrangement. In this case the time investment, love, motivation and intensive day to day training and experience the parents possess can not be duplicated by the non-professional.

Tremendous emotional and financial stress is imposed on the families that have Technology-Dependent children at home. The parents must deal with a complex, confusing, unintegrated medical establishment, a myriad of ancillary services (from equipment vendors, oxygen companies, OT, PT, Nursing agencies, Psychological services,etc.), the public school system, pharmacies, insurance companies, and social service programs. In their communities,they are often socially isolated. Some parents are unable to cope with these daily stressors and the management of their child. Yet if mid-level managers are available to help the parents, their child could come home.

Quality care like financial support entails a flexibility, diversity and individualizing of care to the child and his family's specific needs.

III. COMMITMENT

COMMITMENT to pediatric home care is the final vital link to the survival of home care as an option to parents today. Commitment must begin with the child's family: the parents to each other and to the child.

SECONDLY the medical system must continue to strive for the best for each child. Hospitals are traditionally oriented to acute illness. Chronically ill children and their families are often brushed aside and effectively forgotten, particularly the child that needs intensive technology support. These children will not in all likelihood improve and must remain in a ICU because there is no other facility that can accept them.

THIRDLY, the community must be committed to understand and accept the child and his family. All too often they are socially isolated just at the time that support is so vital.

LASTLY, Our society places great value on science and technology. These children are products of our technological advances in medicine. Five to ten years ago they would not have survived. Though their survival today is assured, the degree to which they thrive, grow, and lead productive and full lives is the degree to which the child and family are offered support when the acute medical crisis is over. The struggle for life is

dramatic and exciting and in many instances is won or lost in a period of days or weeks. Our efforts come to fruition often bringing shining successes as a life is saved. These children however are sometimes left with continuing life-long dependence on medical support, or permanent physical limitations from their illnesses. Over time, the enthusiasm and vigor with which their care is given begins to wane. They do not get better but rather become "chronics". Often times the planning and follow-up then becomes sketchy and the child with complex medical needs is released to an unprepared family.

Our commitment must be as a society to continue to support these children and their families after the acute illness is over and for indeed a lifetime. The quality of their little lives very much depends on our committment as individuals and as a society to supporting and encouraging them and their families.

Initially, the requirements for providing high quality life for many of these technology dependent children sounds overwhelming. The committment of the family, the medical system and the community; the ongoing burden of meeting the requirements to provide high quality cost effective care and the overwhelming need to tap financial resources is no small task but the benefits enjoyed by the child, their family and community and society as a whole are manyfold. A large portion of these children, which medical technology has created and sustained, will one day function as productive, successful individuals of benefit to society. Many will one day "OUT GROW" their dependency on medical equipment and technologies. Though others will require longterm investment, the life they offer will more than warrant the cost we as a society have paid. The case studies and families you will face today will easily prove this point.

I am pleased that we have identified this new medical challange and are actively pursuing the most productive means of providing high quality cost effective care to our new breed of technology dependent children.....

June 1985

My name is Dana Kruse, I am a parent of a special needs child. I am not unique nor one of a kind. If you are also a parent of a special child perhaps you'll hear strains of a familiar tune. If you're a concerned advocate, you know where I'm coming from. If you're working for one of the many agencies designed to help, I hope you'll hear that we need your help. In fact we can't survive without it. We're normal human beings just like yourselves with desires,goals and problems. We ask not for ourselves so much - as from our hearts, for our special children.

First, I'ld like to share some background with you. My daughter Jennifer is now 4 years old. 1½ years ago when she was 2½ years old, she became a near drowning victim. Restored to life by new medicial techniques, she survived where we were told just 2 years prior to those medical advances, she would have died. What we experienced was not the usual child gets sick and then gets better routine. Lack of oxygen to her brain caused massive brain damage and the result is a severely disabled child. For Jenny that means, inability to walk, to talk, to move her arms or clap her hands. She can no longer run, laugh and enjoy life as she had for the first 2½ years of her precious life.

At first life itself was a battle, during which she was hospitialized in a pediatric intensive care unit with 2 bolts drilled into her skull to monitor brain swelling, 24 wires attached to her head to monitor brain activity, 8 I.V. lines in various parts of her body to administer medications that kept her vital organs functioning and stablized her critical condition, she was also respirator dependant.

In an attempt to get her off the respirator, she had a trach put in to help her breath and surgery again later to put a tube in her stomach to feed her because she can't swallow. During her "rehab" hospitalization that lasted 16 months and encompassed 4 different hospitals, she developed a severe seizure disorder. At one point they came continually for over 2 weeks while we tried radical medication treatments to try to regain control over them. Her muscles became so tight, they dislocated her hips which led to surgery which only led to dislocation again several months later. Due to the massive amount of strong seizure medications used over such a long time her bones became brittle which led to 3 fractures in her legs and a broken collarbone. All of which took 3 to 4 months each to heal because she doesn't heal normally anymore. Her weakened physical condition led to illnesses such as pneumonia, flu and chicken pox all of which almost took her life. She also remains in a coma. In January 1985 with the help of the State Insurance Commissioner and our attorney, we encouraged our insurance company to agree to home care and Jenny came home receiving 24 hour a day, 7 day a week LPN care along with needed physical therapy, occupatioanl therapy, equipment, supplies and drugs. We waited for the child we knew to wake up and be better. We looked to the experts in the medical profession for all the answers and discovered they didn't have them. There was frustration and worry we endured over each of these additional crises in her life that have to be endured bacause she doesn't give up. She tries and tries to break out of her shell and the very <u>least</u> we can do is help in every way to assist, support and love her.

During this time we encountered THE SYSTEM...

We met social workers, pediatricians and neurologists, some were understanding and some - were heartless. Institutionalize was the magic word. Take a slice of your heart, a slice of your life - tuck her away and go back to living your lives. Trying to forget the child you love would be taken care of by strangers in a place far away from home that don't love her and couldn't care for her like her family because there is - no love. It didn't take long to learn to be a fighter and learned we had to take control. In the midst of our grief we learned to humble ourselves and ask for help.

We have reduced her care costs by approximately 33% by bringing her home, yet her monthly medical care costs are many times more than our gross monthy salary.

We have been informed by Dr. Dick Gehrz, Head of the Pediatric Intensive Care Unit at St. Paul's Childrens Hospital that no long term care facility or institution would be able to meet Jennifers needs.

We have been told by both the State and Federal Depts. of Health and Human Services that Jenny qualifies for the "Katie Beckett" waiver and/or the chronically ill childrens waiver. Either waiver would provide medical funding for our daughter at home.

Senator Laxalt and Senator Boschwitz, inquiring on our behalf, were informed by letter on March 28, 1985, that Jenny was approved for funding to provide for her home care. Yet when we contacted the Fed. Dept. of HHS to confirm what Senator's Laxalt and Boschwitz had been told, we were informed that the letters sent to both Senators were in error. We were further informed that our applications were still "pending" even though the applications had been on file for months.

The reams of rules and regulations is so mind boggling and discouraging that unless you become determined to sort your way through the maze you give up. I'm afraid some parents do just that, give up.
Medical costs alone are impossible to meet on anyone's salary. Jenny's condition is going to require a longtime or lifetime of medical expenses. If we chose to institutionalize Jenny, the state would pay for her care and all related medical costs and equipment. Because we choose to keep her home we have to constantly battle for financial help that is at the very least degrading and often humiliating.

I believe parents who choose to try should receive willing, supportive help. Everyone has the right to maximize their potential, whatever that might be.

Our family is not unique, we became victims of circumstance and it could just as easily be anyone of you. No one is immune, even if you think you've had your children with no birth problems or no disabilities, there are still grandchildren and accidents happen every day.
So now you've heard some history. I'm here to ask help from all of you to assess the situations you come in contact with. Determine how to best meet the needs of the individual family case through cooperation among agencies each giving, bending, or taking charge as best benefits the family. Most importantly, since you are familiar with the various parts of the system, you can be indispensible in setting up a network to help families find the maximum benefits needed for a total program. Seeing where you can expand existing programs and creating new ones.
The families at best are already encumbered with stress of care and stress of coping and often don't have time left over - let alone the energy or fortitude to struggle with the system. Many times they give up before they go through any more hassle.

Be that bridge for families -

Be the voice of support-

Be the person that makes the difference to these families-

We need you-

We want to work with you and be understood by you, let you share our joys and most of all allow you to know our special children.

We are determined to keep Jeny at home, determined to give her every opportunity to maximize her potential and determined to persevere through whatever we must, to do so. We hope you will strive with us to provide the most possible - for all our special children, whatever their needs may be.

Thank you.

Dana

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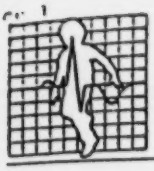

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June 6, 1985

I would like to share with you the story of my daughter Judy. I am hoping that Judy's story will help you to understand some of the frustrations and fears we as a family shared in order to restore to our daughter some array of happiness and potential that had been taken from her.

When our little girl was born on Jan. 25,1975 my husband and I were floating on a cloud. We had a little girl. We had such plans for her. Then came reality. When Judy was two years she suddenly became ill. I had no idea what was the matter with her except her breathing did not look normal. I called her doctor whoes office is located at Children's Hospital of Phila. Once he assessed Judy he insisted we admit her to the hospital. Judy had suffered a spontaneous atelectasis in her right lung. Little did we know Judy would remain hospitalized for the next six months. The next few days after Judy had been admitted were like a nightmare. In just two days time our healthy little girl had become our critically ill little girl. As time went on it became more and more apparent that Judy would remain ventilator dependent. Because of the uncertainely of Judy's medical stability it was suggested we remove her from the ventilator and allow her a peaceful exodus. You have to understand Judy was alert and emotionally responding to us. This is why our decision was so easy. Judy looking at us with her big brown eyes asking for our help, our decision would be to help and support her as much as possible. As time went on we were told Judy's survival would depend on medical technology. We talked to Judy's doctors and told them of our plan to take Judy and her ventilator home. Her doctor looked at us and said, "That's Impossible" we can not allow you to take a ventilator dependent child home to live. I answered Oh, try and stop me.

This is where our story really begins. Judy was moved from an acute setting to a intermediate setting. Where there were nine other long term ventilator assisted children. The first question I was asked was, Who will care for Judy at home? My answer was I will and I immediately started learning and doing all of Judy's care. The next question came up who will manage ventilator at home. I assured the nurses that I wouls also learn this care. A respiratory therapist had been asked to explain Judy's ventilator to us, which was a Emerson Volume Ventilator and about the size of a washing machine. My husband and I had several weeks of training from the respiratory therapist until we both felt confident

in our handling of Judy ventilator. Now came the third question who will pay for Judy care at home. I checked with our insurance company and found they would pay 80% of Judy's care at home until we reached our life time maximun. I talked to the hospital social worker assigned to our case and she agreed to look for alternative funding for us. The doctors and nurses had prepared a list of equipment that Judy would need at home. I called several medical supply stores only to discover that it was impossible to purchase a ventilator, they were only sold to institutions. I went back to Children's Hospital with this information. By now, they realized I was very serious about bringing Judy home so the hospital agreed to purchase the ventilator for me and then I could purchase it from them. One more obstacle out of the way. The social worker was not very successful in obtaining alternative funding. She came up with all negative responses. At this time of year the Catholic Church holds their annual Catholic Charity Appeal. Listening to this announcement in church on Sunday, I thought why not give them a try. I called first thing Monday morning and to our absolute delight found that a benefactor had opened a special account that Judy would fall into so they would be able to give us the additional funds needed to purchase Judy equipment. We were finally making headway. In October of 1977 it was suggested I apply for a medical care for Judy, I was told to go to my local social security office. Once there I was told when Judy had been hosptialized for 30 calender days she would be eligible for SSI benefits and a medical card. Judy had already been hosptialized for four months at this time. I went back to the social worker with this information. She was not aware of this ruling. As time gotcloser for Judy to come home we became more anxious to have her there. The hold up was the ventilator. Seeing my depression the hosptial agreed to lend me a ventilator until ours arrived. Our plans were set.

On November 21, 1977 our beautiful little girl was sent home to die, or so her doctors thought. This day had a triple meaning for me. It was my youngest sons second birthday, Judy came home to live with her family, and I met Robert G. Kettrick M.D. who was to be our trouble shooter for Judy home care. Dr. Kettrick is now director of the pediatric intermediate unit at Children's Hospital of Phila. I had agreed to 8 hours of nursing a day for Judy. I cared for her myself the other sixteen hours. Because our house was small and Judy's bedroom could not hold her and her equipment,

we turned our dinning room into a room for Judy. We had no night nurse so my husband and I slept on the floor next to Judy's crib for the first six months she was home.

Because we brought Judy home the parents of the other nine children had decided they too could bring their ventilator assisted children home to live. Over the next year everyone of these nine children came home to live, under the direction of Dr. Kettrick with out really having a program just addressing each need as it came up. Once Judy came home her daddy income was deemed hers and she became ineligible to receive SSI benefits and her medical card. It seemed we could institutionalize Judy and receive help from the government but because we wanted to care for our daughter ourself and because we wanted her to live at home we were penalized. We persued this ruling all the way to the federal level. We even initated a law suit against Patricia Robert Harris , who at that time was the Secretary of Health and Human Services. All our efforts proved fruitless Judy's benefits were still denied. However we indeed were laying the ground work for the policy change that occured in Nov. 1981 when the first SSI deeming waiver was granted.

Judy's insurance had a life time maximum that we were quickly reaching. We had to come up with Plan B. We contacted our local congressman, we went to Washington and appeared before Senator Kennedy's sub-committee on National Health, we met with Senator Heinz and Senator Schweiker. Everyone we talked to agreed we had a problem but no one had any answers. Myself and the parents of the other nine children who had been discharged from intermediate held together. We formed a group called Concerned Parents of Ventilator Assisted Children of which I was president. We held meetings at my house and we invited everyone we could think of that might be able to help us on the local, state, and federal level. One day I stopped in at a conference and I heard State Representative Mary Ann Arty, who is also a nurse speak. I knew she was the person to help us. I contacted her office and explained our problem. She assurred me she would help and support us. Mary Ann put a house bill together for us. This was 1979 The International Year of the Child. One day looking through the mail I saw an enevelope with a return address belonging to Governor Richard Thornburgh, the Governor of the state of Pa. Inside was an invitation to the International Year of the Child Press Conference to be held in Harrisburg. We were delighted. Attending the press conference we learned that one of the Governor's objectives for the year of the

child was to support the bill initated by State Rep. Arty , this would give the ventilator assisted in the state of Pa a line item in the budget. I was right Mary Ann had been able to help. One problem was solved but another one appeared. How was the money going to be distributed. Everyone seemed to have different opinions Our parents group also had their opinion. I made several trips to Harrisburg and I attended several meetings at Children's Hospital. Finally we all agreed that Dr. Kettrick would oversee our program. I also insisted that the majority of the money be used for patient care. The place were the money was needed most. The Ventilator Dependent Children's Home Program in the state of Pa. was formed. This program is used as a National Model Program.

Meanwhile Judy was beginning to be our happy little girl again. The twinkle was back in her eye, the smile was back on her face, she was improving by leaps and bounds. We were now able to have 24 hour a day medical management for Judy and we had a complete educational program for her at home consisting of a special education teacher, a physical therapist, and a speech therapist.Our scrawny little girl who weighted 12 pounds and could not tolerate even ½ strength skin milk upon discharge from the hospital was becoming a chubby angel face little girl. I am not saying every thing ran smoothly at home in fact we have Murphy's law hanging on our wall which says if anything can go wrong it will and on most days it did.

In 1982 with the increasing number of children wanting to come home the funds from the Ventilator program could not be stretched far enough. Because Judy's insurance had ran out we had to depend entirely on the program for Judy's funding. The dollar sign once again became more important than the care of the children. It was time to once again start lobbying. Because I had laid the ground work five years ago, I was able to go to Secretary of Health and Human Resources Schweiker and through him apply for a deeming waiver for Judy. Because Judy was the first person in the stae of Pa. to have the waiver the state agencies did not know to handle it. It was sent from agency to agency and the letters and the calls began again. Eventually we received $1.00 per month from SSI. This entitled Judy to medical card. My calls began to Harrisburg to determine exactely what medical assistance would provide. On Judy's ninth birthday we received the best present of all, medical assistance had agreed to pay for 16 hours a day of nursing for Judy. The supplies not paid for by medical assistance would be paid for by the ventilator program.

These people all loved and cared for Judy as much as we did. Through Judy's life and death we have paved the way for many other children who survival depends on medical technology to enjoy home care. Pennsylvania holds the history and foundation for home care. It is stories like Judy's that support this foundation. Because of the Ventilator Assisted Children's Home Program and because of the policy changes that have occurred and through our achievement in educating the community to the awareness and acceptance of home care, A family no longer is told home care is impossible. We have been successful in bringing about the realization of the importance of home care to the growth and the development of the child and the family. We must remember that the family can not do it alone they need the love, sharing, and giving of one another to bond us together to make aplace for this new generation of children created by medical technology.

Betty Wingel
Director SKIP of Pa.

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HOME CARE FOR THE CHILD WITH CANCER[1]

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The purpose of our study, "Home Care for the Child with Cancer", was to examine the feasibility and desirability of a home care alternative to hospitalization for children dying of cancer. Home care was defined as "the delivery of services, nurse-directed with physicians and other health care professionals as consultants, to enable parents to give comfort and care as required by a child at the end stage of life."

A pilot study was done from 1972 to 1975 in which home care was offered to eight families. In five families, the child did die at home. Based on this nonfunded pilot study, a federal grant proposal was submitted to the National Cancer Institute, Department of Health, Education and Welfare, and the project was funded in 1976. There were two research phases during the four years of the study. For the first two years, the grant provided staff who directed the nursing care of children with cancer at the end stage of life. During this time, collaborative arrangements were being developed with public health nursing and three hospital/clinic-based institutions. The grant staff organized and provided the actual care, and collected data on this care. During the third year, the coordination of the care, both directly and indirectly, was essentially turned over to three already existing health care organizations and to the public health nurses utilized by these institutions. In the fourth year, the grant staff then devoted their full attention to the question of the desirability of home care, and to the observation of what was happening in the three institutions. This was done to

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help answer questions regarding the feasibility of the institutionalization of this home care alternative.

The criteria for referral of terminal cancer patients to the study included the following: (1) the patient was 17 years of age or younger; (2) the patient had some form of cancer and was expected to die fairly soon as a consequence; and, (3) no procedures requiring inpatient hospitalization were planned. Whether the child met both the second and the third criteria were determined by the child's pediatric oncologist.

The services available for the family were as follows:

1. The nurse would be on call 24 hours a day, seven days a week.

2. The nurse would be available to help the family members, who were the primary care givers dealing with problems that might arise.

3. The nurse was available to make home visits whenever and wherever the family desired such contact.

4. The option of the child returning to the hospital was always open.

5. The child's physician could be called at any time.

During the first two years, 64 children were referred to the project: of those, 58 died. Sources of referrals for these 58 children were as follows: More than 50% were from the University of Minnesota; St. Louis Park Medical Center in Surburban Minneapolis provided the next largest number; and 15 children were referred from eight other hospitals. A total of 23 physicians were involved: Fourteen from the University of Minnesota, two from pediatric oncologists at St. Louis Park Medical Center, and, seven other physicians representing eight other hospitals.

The places of death for the 58 children were as follows: Forty-six (79%) at home, twelve (21%) in the hospital, with one of these children dying in a hospital in Mexico, and one child dying in an ambulance while returning to the hospital.

The range of ages of the children who died at home was one month to 17 years, with the largest number (13) being in the age range of 15 to 17. The ages of children with cancer who died in the hospital ranged from 3 to 17 years. The data suggests that the age of the child is not a significant factor in determining the feasibility of home care.

The period of time from diagnosis to death for the children with cancer ranged from less than three months to over nine years. The length of home care to death varied: Fifteen families were involved with home care for less than one week; four families, 1-2 weeks; seven families, 3-4 weeks; sixteen families, 1-3 months; and four families, over 3 months.

The direct professional nurse involvement for the 46 children who died at home was an average of 13.8 home visits, with a range from 1 to 110. The total number of professional nurse home visits for the 46 families, who had a child die at home, was 634 visits. A nurse spent a mean of 31.5 hours per family (range of 1 to 305.6). This home contact was supplemented by telephone calls. These ranged from one family who made no phone calls to the nurse, to another family who made 101. The mean number of calls per family was 22.7. Duration of telephone time during home care averaged 4.1 hours per family, with a range from 1 to 23.5.

Families who participated in our project resided in both urban and rural areas throughout Minnesota, North Dakota, and Wisconsin. Using the Hollingshead Two-Factor Index of Social Position (Hollingshead, 1958), we classified the families of the children who died at home from highest through lowest category 1-5, respectively. Forty-eight percent were the two lowest categories, while 22% were in the two highest categories.

There were 107 siblings in the families of the 46 children who died at home. Seventeen were between one and five years of age, the largest number of siblings were between the ages of six and ten years of age. In five families, the dying child was the only child; in another five, there were nine siblings in the family.

Parental status is also of interest. Fifty-four families were two-parent families and in four there was only one parent in the home. Three of these families were mother-only, and one was a father-only family. In the four single parent families, three of the children died at home, including the one headed by the father.

The place of death in the home for 31 of the 46 children was in the living/family room, essentially the center of family activity. The majority of the children wanted to be involved by seeing and hearing what other family members were doing. These children wanted to be near the family.

There were 58 nurses who worked with the families: twenty-four were hospital based; twenty-two were involved in public health nursing agencies; two were nurses on the grant staff; five were unemployed; and five were in related areas such as school nursing. We looked at the number of families cared for by these nurses and found that 13 families were assisted by a hospital nurse, either

from the referring institution or from a local hospital. Eighteen of the families were assisted by a public health nurse, six by the home care staff nurses, seven by unemployed nurses, and four by other nurses.

A few of the families had two co-primary nurses; three families had two hospital nurses; one had two public health nurses; and six had a combination of a hospital nurse and a public health nurse. We noted that less consultation with the project staff was required with the combination hospital nurse and public health nurse team. The hospital nurse was able to handle the emergency-type questions, and the public health nurse was able to handle situations requiring knowledge of local resources. An interesting observation that has evolved from this is the need for more nurses to "nurse-network'.

The age of the home care primary nurses ranged from 23 to 63 years. The experience ranged from one to 44 years since they had become registered nurses (RNs). Seven of the nurses had Master's degrees, 29 were baccalaureate nurses, four were nonregistered nurses, and the balance had hospital diplomas. The four nonregistered nurses included three licensed practical nurses and one student nurse.

The number of physician home visits through the time of death and immediately after the death of the child for the 58 families were as follows: Forty-four of the families did not have a physician visit at home, nine of the families had one physician visit; one family had two physician visits; two families had four physician visits; and one family had 17 home visits, including twelve visits by a psychiatrist.

Home visits by other health care professionals for the 58 families included; a laboratory technician who made one visit to three families and two visits to one family, an X-ray technician who made a visit to one family, an occupational/recreational therapist who made one visit to one family, a chiropractor who made seven visits to one family, a Home Health Aide who made one visit to one family and 43 to another, and a homemaker who visited one family 16 times.

Although no social worker made a home visit during the time of home care, data indicates social work involvement before referral to the home care project as well as with family following the death of the child. The reason for no home visit by social workers during home care was that the families who were involved with a social worker lived away from the medical center, and there were no social workers available locally.

With regard to the cost effectiveness of home care, we looked at cost figures as requested by insurance companies. For 46

children who died at home and on whom we had data, the duration of final care days at home was a mean of 38.9 days with a cost estimate of $1,218, a median of 20.5 days with a cost estimate of $705. This cost estimate is based on the cost of nursing services at the rate of $10. a day to be on call 24 hours a day and for telephone consultation, $45. per home visit, and $10. for a clinic visit. In discussions with insurance companies, they urged us to use a comparison group. The first group we utilized was a group of 22 children who had died at the University of Minnesota Hospital prior to 1976 and before our project was funded. The 22 children who died of cancer at the University of Minnesota Hospital had a mean duration of final care of 29.4 days, with a cost estimate of $5,880. based on the cost of nursing service and room and board at the rate of $200. per day. The median was 21.5 days, with a cost estimate of $4,300.

We have recently updated these cost figures. We have estimated a daily cost of home care per child at $51.79 which includes $40.04 per day for nursing care, based on $35. for the first hour of a visit and $10. for each additional half hour; $3.57 for room furnishings; $3.49 for equipment; $2.99 for supplies; $2.54 for medications; and, laboratory tests accounted for $0.14 per day. No cost was included for room and board because the family provided this. Constrasting the cost per day for a child who died in the hospital while receiving comfort care only was $279.91. This included $158.09 for nursing care, room, and board; $27.69 for supplies and equipment; $12.94 for medications; and, $81.19 for laboratory tests. The hospital based costs are thus about five times more than the home based costs.

The approach to assessing the results of home care have been guided by considerations of feasibility and desirability. Feasibility and desirability are not easily separated. Before something can be adjudged "desirable", it must first be demonstrably feasible. In that sense, both desirability and feasibility can be thought of as lying on the same continuum, with feasibility at a lower or more basic level, and desirability at a higher level. Thus, some "threshold" level of feasibility must be achieved before an assessment of desirability can take place. For some distance along the continuum immediately after this threshold level, it is very difficult to distinguish between desirability and feasibility. In a pure sense, the process is feasible. However, if that process is much more costly (in monetary or other terms) than existing alternatives, some would argue that the process is not feasible while others would couch that argument in terms of (non)desirability. If there are no immediate and obvious concerns about its "feasibility", the assessment can move to a higher level where an assessment of the desirability of the process becomes the focus.

The second consideration derives from the need to operationa-

lize the distinction discussed above. Because the process of home care was at a very early stage of development at the beginning of the project, the first concern was to demonstrate the feasibility of the process at the basic threshold level. We believe the study has demonstrated the basic feasibility beyond debate. The next level of assessment is the focus of the second part of this paper.

The effort in this area has been directed to determining whether or not there are important negative consequences to home care for the family, the professionals or others involved in the care of the dying child. Because the project has been concerned with developing the home care model in practice and with assessing these basic levels of feasibility and desirability, the study design had not included statistically relevant control groups or random assignment of cases to various levels of care. Rather, the approach has been one of ruling out negative consequences of home care. At a somewhat higher level on the feasibility-desirability continuum, basic positive consequences of home care are also discussed. However, questions related to the highest order of desirability, particularly in contrast to other modes of care, remain to be answered in other study designs.

The intent of Phase One of the project was to develop and put into practice a model for home care of children dying of cancer. In Phase Two, the intent was to move the provision of that care from the research project to the community, to institutionalize home care in existing health care delivery organizations.

Place of Death

The first result of home care is the place of the child's death. Because home care was intended to permit families to care for their children at home through death, the proportion of children who received home care but died in hospital could be an indicator of the degree to which the model worked. In Phase One, 12 (20%) of the 58 children who received home care died in hospital or en route to hospital; four (22%) of the 18 Phase two children died in hospital. Thus, about one-fifth of the children who entered home care returned to a hospital to die. The following sections discuss the differences between home care cases where the child died at home and those in which the child died in hospital.

Differences in Personal and Family Characteristics

There were no differences between Phase One families whose children died at home and those whose children died in hospital in terms of religion, family size, socioeconomic status, rural-urban residence, gender of child, or child's order of birth in the family. In sum, there is no relationship between place of death and any of

the personal and family characteristics measured.

Differences in Diagnoses and Physical Condition of Children

Table I shows that there are few differences in diagnoses between children who died at home and those who died in hospital. The only diagnosis where there are more hospital deaths is the lymphoma category. However, since there are only very few cases involved, no significance test could be done.

Table I

Diagnoses of 58 Children who Received Home Care and Died During Phase One Home Death versus Hospital Death

Diagnosis	Children who Died at Home		Children who Died at Hospital	
	Number	Percent	Number	Percent
Leukemia				
ALL	8	17.4	4	33.3
AML	6	13.0	1	8.3
Other	5	10.9	0	-
Lymphoma				
Burkitts	3	6.5	0	-
Undiffer.	1	2.2	1	8.3
Histiocytic	0	-	1	8.3
Hodgkins	0	-	1	8.3
Neuroblastoma	4	8.7	1	8.3
Central Nervous System				
Medulloblas.	2	4.3	1	8.3
Astrocytoma	3	6.5	1	8.3
Brain stem glioma	2	4.3	0	-
Bone				
Ewings sarcoma	4	8.7	0	-
Osteogenic sarcoma	2	4.3	0	-
Other				
Ependymoma	2	4.3	0	-
Malignant histiocytosis	1	2.2	0	-
Malignant teratoma	1	2.2	0	-
Embryonal cell carcinoma	1	2.2	0	-
Rhabdomyosarcoma	1	2.2	0	-
Hepatoblastoma	0	-	1	8.3
Total	46	100.0	12	100.0

Table II

Comparison of: Physical Symptoms of Children who Received Home Care and Died during Phase One with Children Dying in the Hospital

Symptom	Children who Died at Home		Children who Died at Hospital	
	Number	*Percent (of 46)	Number	*Percent (of 12)
Difficulty breathing	32	69.6	4	33.3
Difficulty drinking	32	69.6	4	33.3
Difficulty eating	35	76.1	1	8.3
Bleeding	20	43.5	4	33.3
Mild	(5)	(10.9)	(0)	
Moderate	(13)	(28.3)	(3)	(25.0)
Severe	(2)	(4.3)	(1)	(8.3)
Vomiting	19	41.3	4	33.3
Seizures	13	28.3	2	16.7
Tumors, external	11	23.9	0	-
Decubitus ulcers	7	15.2	1	8.3
Diarrhea	7	15.2	1	8.3
Abscess	4	8.7	2	16.7

*Children generally had more than one symptom, hence the percent will total more than 100.

Beyond the global designation of the child's diagnosis, one could anticipate that there may be certain aspects of the child's physical condition that would make hospital readmission more likely. However, Table II shows that only two of the 12 recorded symptoms occurred with a greater proportion among children who died in hospital than among those who died at home--severe bleeding and abcesses occurred with a somewhat higher proportion among home care children who died in hospital. While these occurrences involved a total of only three children, in each case interviews with the parents indicated that the occurrences of the symptom was highly related to the parents' decision to return the child to hospital where the children subsequently died. It should be noted, however, that in two of these three instances, there was parental dis-

satisfaction with nursing care. However, these same symptoms also occurred in home care children who were not readmitted and who remained at home through death. Thus, while some families were more comfortable in re-hospitalizing children with abscesses or severe bleeding, others chose to keep children with those symptoms at home. There is, therefore, no evidence to suggest that home care is necessarily inappropriate for children with certain symptoms. On the other hand, it is probable that the occurrence of certain symptoms in the absence of immediate support may lead some parents to readmit their dying child to the hospital.

Differences in the physical condition of children receiving home care were assessed at the time of admission to home care, at one week prior to death, and at six hours prior to death. These periods were chosen to provide an overall description of the children as well as a vehicle for comparison of nursing services required and the difficulties encountered by parents.

Information describing the physical condition of each child was abstracted for the three selected periods. While some nurses gave less complete descriptions than others, and the time periods in question were not always observed because of the short duration of home care, descriptions of physical condition at time of admission

Table III

Ratings of Physical Conditions of 46 Children who Died at Home During Phase One of Home Care

	Admission		One Week Prior to Death		One Week Prior to Death	
Total number of children	46		46		46	
Total with complete information	45		30		46	
Total with agreement of at least two raters	45 100% of 45		30 100% of 30		46 100% of 46	
Ratings for each time period:						
A	6	13%	1	3%	0	
B	35	78%	24	80%	7	5%
C	4	9%	5	17%	30	85%
Total	45	100%	30	100%	46	100%

were done on 75 (99%) of the 76 children who received home care and died during Phases One and Two. As shown in Table III, information for the period six hours prior to death was available on 68 (90%) of the children, while information for the period one week prior to death was available in only 47 (62%) of the children. The absence of this data is in great part because many of these cases entered home care less than six days before the child died.

Three cards were prepared for each child; each card was identified with a code number, including the child's age and designation by time period as Card I (admission), Card II (one week prior to death), and Card III (six hours prior to death). If the chart did not contain a description of the child at the time period in question, the card was marked "no information available." Thus, 228 cards were prepared--three cards for each of 76 children.

Research staff examined several existing scaling techniques, including an adaptation of the Karnofsky scale (1953), Eastern Cooperative Oncology Group (ECOG) scale (CROP Newsletter, 1978), and Host Performance scale (CROP Newsletter, 1978) to determine their applicability to this study. However, no existing instrument was appropriate for describing the physical condition of children varying from one month to 17 years of age who were dying. As a result, a scale specifically adapted to these children was developed. Drawing from the existing instruments, this scale considers physical characteristics and psychosocial aspects that might occur in these children. Because the intent was to characterize the condition of these children in broad terms, three classifications were developed:

A. Attending school: ambulatory, responsive and interacts well, sleeping well, age appropriate skills and good intake and output.

B. Unable to attend school: ambulatory with help or bedridden, responsive and interacting some of the time, needs assistance with sleeping, control of symptoms and activities, and some interferences with intake and output.

C. Bedridden: not responsive and not interacting, requires special care and assistance with any activity, very limited or no eating or drinking, and diminished or no output.

As intended, progression from A to B or B to C includes increasing severity of symptoms, advancing physical disability, increasing need for assistance, and decreasing communication by the child. Thus, a child with a rating of "C" was more severely affected by his illness than a child with a rating of "A" or "B" and probably required more care. Descriptions of "B" and "C" would describe most hospitalized terminally ill children.

Three nurses independently assigned ratings of "A", "B", "C"

or "Insufficient Information" to each of the 228 cards. All three nurses had extensive experience in pediatric nursing; two had completed post-master's course work in family social studies and the third was a doctoral candidate in hospital and health care administration. The raters were unaware of the histories of the children and did not know whether they died at home or in the hospital. The raters were instructed to view each card from the perspective of a public health nurse visiting a child in the home. They were instructed to assess the child's condition for a research study, rating the child as either "A", "B", or "C".

An example of the narrative included in the cards as follows: Sample Card II. Age six months.

> The child is sitting on her mother's lap. She is whimpering at times. The mother states the child is taking a limited amount of fruit juices. She is constipated. She was very restless during the night and voided once. She dozes at short intervals but appears to respond to her mother's voice.

All three raters independently agreed on a "B" rating for this card.

Table IV

Ratings of Physical Conditions of 12 Children who Died in Hospital During Phase One of Home Care

	Admission		One Week Prior to Death		Six Hours Prior to Death	
Total number of children	12		12		12	
Total with complete information	12		7		7	
Total with agreement of at least two raters	12 100% of 12		7 100% of 7		8 100% of 8	
Ratings for each time period:						
A	2	7%	0	-	0	-
B	10	83%	6	86%	2	25%
C	0	-	1	14%	6	75%
Total	2	100%	7	100%	8	100%

Tables III and IV separate the ratings of physical conditions for the 46 Phase One children who died at home and the 12 who died in the hospital. Comparison of Tables III and IV shows almost no difference in the ratings of physical conditions between children who died at home and those who died in hospital. This finding suggests that the 12 children who died in the hospital did not exhibit any increased physical disability or severity of symptoms as compared with the 46 children who died at home. It is probable that the children who died in the hospital were not more severely affected by their disease than were the children who died at home.

Differences in Home Care Services

Various aspects of the home care received by children who died at home and in hospital were examined to assess whether they were related to the place of the child's death. The length of time in home care shows no major differences between the two groups. Fifty-eight percent of the children who died in the hospital and 48% of those who died at home received home care for a number of days which falls below the median for the combined group of 58 cases. However, there is some evidence to suggest that children who died at home received a more intensive level of care than those who died in the hospital. Table V shows that the 46 children who died at home received more home visits from home care nurses than did the 12 children who died in hospital. The relationship between dying at home and rate of home visits is significant at the .02 level (Mann-Whitney U). Table VI shows a similar difference in the rate of telephone calls to the family by home care nurses which, however, is not statistically significant.

A similar difference exists in the medications received by home care children. Table VII shows the number of medications used at home during home care by children who died at home and by those who died in hospital. There is a significant relationship at the .05 level between place of death and use of medications.

Table V

Rate of Nurse Home Visits Per Day of Home Care During Phase One

	Rate for 46 Children Who Died at Home	Rate for 12 Children Who Died in Hospital
Median	.42	.21
Range	0.06 - 3.0	.03 - 67
Mann-Whitney U = 381.5; $\bar{z}$ = 2.02; p = .022 (one-tailed)		

Table VI

Rate of Telephone Calls Per Day of Home Care During Phase One

	Rate for 46 Children Who Died at Home	Rate for 12 Children Who Died in Hospital
Median	.61	.50
Range	0 - 3.67	.07 - 3.0
Mann-Whitney U = 317.5; $\bar{z}$ = .80; p = .21 (one tailed)		

Table VII

Number of Medications Used at Home During Home Care of 58 Children Who Died During Phase One

Number of Medications	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
0	0	-	1	8.3
1	4	8.7	1	8.3
2	6	13.0	3	25.0
3	6	13.0	0	-
4	5	10.9	2	16.7
5	7	15.2	3	25.0
6	3	6.5	2	16.7
7	4	8.7	0	-
8	3	6.5	0	-
9	1	2.2	0	-
10	3	6.5	0	-
11	2	4.3	0	-
12	2	4.3	0	-
Total	46	99.8	12	100.0
Mann-Whitney U = 359.5; $\bar{z}$ = 1.60; p <.05 (one-tailed)				

Table VIII

Types of Medications Used at Home for Pain Control
During Home Care In Phase One

	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
Narcotic Analgesic	37	80	5	42
Antianxiety Medications	35	76	6	50
Nonnarcotic Analgesics	16	35	5	42
None of the above	0	-	1	8

Table VIII shows that home care children who died at home were more likely to receive narcotic analgesics and antianxiety medications for pain control than were home care children who died in hospital. The frequency of use of nonnarcotic analgesics was about the same in the two groups and the only children who did not receive pain medication at home died in the hospital. Table IX shows this relationship also holds true for medications other than those used for pain control. In most of the medication categories shown in Table IX, children who died at home were at least as likely as children who died in the hospital to receive medications. "Antibiotics" is the only category in Table IX in which children who died in the hospital were much more likely to receive the medication.

Tables X and XI show that the difference in "intensity" of service between children who died at home and those who died in the hospital also holds in the areas of supplies and equipment. Children who died at home used or had available more supplies and equipment than children who died in the hospital.

These data (Table IX - XI) on the "intensity" of home care services clearly show a difference between Phase One home care children who died at home and those who died in the hospital. However, that difference is not in the direction one might hypothesize in trying to determine why some children were readmitted. While one might anticipate that the children who required more intensive home care would be more likely to return to the hospital, these data suggest exactly the opposite--children who received more intensive home care were more likely to die at home. This finding suggests an alternative explanation that parents of children who

Table IX

Types of Medications Used for Symptom Control, Other than Pain, at Home During Home Care in Phase One

Medication	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent (of 46)	Number	Percent (of 12)
Corticosteroids	16	34.8	2	16.7
Laxative/enema/ stool softener	15	32.6	2	16.7
Antiemetic	10	21.7	3	25.0
Antibiotic	3	6.3	4	25.0
Sleep-inducing	8	17.4	0	-
Cough medicines	5	10.9	0	-
Antiallergy	4	8.7	0	-
Antihistamine	3	6.5	0	-
Antacid	2	4.3	1	8.3
Antifungal	2	4.3	1	8.3
Vitamin	2	4.3	1	8.3
Antiseizure	2	4.3	0	-
Eye lubricant	2	4.3	0	-
Antidiarrheal	2	4.3	0	-
Diuretic	1	2.2	0	-

died at home were more committed to and more involved in home care, and thus developed and provided a more intensive type of care, than parents of children who died in hospital. In summary, there appears to be a strong indication in Phase One that families who mounted more intensive home care efforts were more likely to have their children die at home.

Information from interviews with parents after the child's death suggests that decisions to return the child to the hospital were hardly ever related to the process of home care. Table XII shows a summary of the reasons parents gave us as to why they decided to readmit their child to the hospital. It is clear that

Table X

Various Room Furnishing and Equipment Used During Home Care in Phase One

	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent (of 46)	Number	Percent (of 12)
Room Furnishing:				
Urinal/bedpan/ commode	26	57	0	-
Wheelchair	14	30	5	42
Overbed/bedside table	8	17	2	17
Hospital bed	7	15	1	8
Emesis basin	6	13	1	8
Hospital gown	4	9	1	8
IV standard	3	7	0	-
Bathtub safety equipment	2	4	0	-
Walker	1	2	0	-
Stretcher	1	2	0	-
Equipment:				
Antipressure devices	27	59	5	42
Suction machine and apparatus	7	15	1	8
Oxygen and apparatus	5	11	0	-
Humidifier	5	11	0	-
Blood pressure equipment	5	11	0	-
IV fluids and apparatus	4	9	0	-
Feeding tubes and food	3	7	0	-
Hot water bottle	2	4	0	-
Neck support	0	-	1	8
Whirlpcol/sitz bath	0	-	2	17

Table XI

Medical Supplies Used During Home Care in Phase One

	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent (of 46)	Number	Percent (of 12)
Incontinence pads	30	65	5	42
Dressings	21	46	3	25
Syringes/needles/swabs	12	26	2	17
Mouth care swabs	9	20	0	-
Urinary drainage equipment and supplies	7	15	1	8
Gloves	5	11	2	17
Antiseptics	5	11	2	17
Enema supplies	4	9	0	-
Masks	1	2	0	-
Tongue blades	0	-	1	8

multiple factors entered into each family's decision. However, these reasons can be grouped into several major categories. One major category includes such personal reasons: "I couldn't go past the room if he died in there"; "I didn't think it was any good for his sitter"; and, "I was afraid her sisters would never want to sleep in their room again." (families 1 - 4). Another category includes reasons suggesting that the mother, as primary caregiver, felt anxious, overburdened and exhausted and had become sufficiently comfortable in the hospital to utilize the hospital facilities to aid her in caring for the child (families 5 - 7). Medical problems such as sudden and acute pain, respiratory distress, and status epilepticus constituted a third category (families 8 - 10). The family that wished their child to receive Laetrile treatment in a hospital did not readily accept nursing visits and had apparently planned a Mexican hospital admission prior to the nurse's first home visit. In addition, families 4 and 8 did not feel they had adequate nursing services.

The delivery of home care services was the major reason cited by a parent in three cases. In one instance, the parent felt that

Table XII

Reasons for Return to the Hospital for 12 Children Who Received Home Care During Phase One and Who Died in Hospital

Family	Reason(s) for Return of Child to Hospital
1	Father and siblings did not want child to die at home; died in ambulance en route to hospital.
2	Child requested return home. Mother told physician and nurse that she didn't want child to die at home. Parents felt that some medical treatment might still help.
3	Child and parents sought readmission to control sudden, severe pain. Mom also related inadequate rest, fear of the death event, and fear the siblings wouldn't be able to use their room again if child died in it.
4	Mother said she planned on rehospitalization when child dying. Felt overburdened at home and more secure in hospital. Mother felt the nurse did not offer enough assistance with physical care.
5	Mother felt anxious, exhausted, overburdened, that home care was too much responsibility for her.
6	Mom anxious, exhausted, concerned that she couldn't help quickly enough. Father felt that the child's presence in home was not good for siblings, nor himself.
7	Mother felt anxious, overburdened and alone in caring for child at home, felt more secure in hospital. Could sleep at night knowing that nurses were responsible. Physician seen as encouraging hospitalization.
8	Child developed respiratory distress. Child requested return to hospital. Family unable to reach nurse and felt lack of support from nurse.
9	Child developed pain, requested return to hospital to establish pain control and to stay overnight. Died before discharge. Mother later reported fear of what death would look like.
10	Mother planned death at home, child readmitted for transfusion when rectal bleeding began. Mother felt poor physician support prevented death at home.
11	Father not accepting of death and cessation of chemotherapy. Family went to Mexico for Laetrile.

Family	Reason(s) for Return of Child to Hospital
12	Rehospitalized for control of status epilepticus. Mother said she wouldn't be able to stand seizures at home.

the physician failed to communicate adequately the seriousness of the child's situation and was not sufficiently supportive of home care. Insufficient nursing services were cited by the other two families. In one case, the family apparently chose to return to the hospital when the nurse failed to respond to their telephone call. In the second family, the mother had always planned on returning to the hospital before the child died.

Differences in Physician Services

The 12 children who died in the hospital were cared for by eight physicians, six of whom cared for one child, one who cared for two children, and one who cared for four children. The latter physician was involved with a total of six of the 58 cases in Phases One through Four, (67%) of his patients died in the hospital and two (33%) died at home. The physician who cared for two of the children who died in the hospital also provided care to four children who died at home. Physician attitude was cited as a cause for return in only one of these cases (family number 10 in Table XII). In none of the other 11 cases was this an apparent factor.

Table XIII shows that in Phase One, there was little difference in the number of physician home visits between children who died at home and those who died in hospital--in both groups, less than one-fourth of the children were visited at home by their physician.

Table XIV shows a difference in both phases in the number of clinic visits between children who died at home and those who died in the hospital. In each phase, children who died at home were twice as likely as children who died in the hospital to visit their physician's office or clinic. A possible conclusion that might be drawn from Tables XIII and XIV is that children who are hospitalized are seen in the hospital by their physicians and are, thereby, much less likely to either need or receive home visits or clinic visits. Alternatively, one might conjecture that difficulties encountered either in transporting the child from home to the clinic or in encouraging the physician to make a house call may have contributed to parents' decision to readmit their child to the hospital before death. However, the absence of supporting data from other parts of this study would lead to the conclusion that return to the hospital was not related to availability of physician services.

Table XIII

Physician Home Visits Prior to Death During Home Care in Phase One

No. Visits	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
0	35	78.1	10	83.3
1	4	8.7	1	8.3
2	3	6.5	1	8.3
3	3	6.5	0	-
17	1	2.2	0	-
Total	46	100.0	12	99.9

We have attempted to discover whether or not the parents were satisfied with the home care services provided. One of the ways we looked at this was to have the parents rate their choice of care if they had to choose over again. Of the mothers and fathers, 97% said they would definitely choose home care, one might choose home care, and one mother said she would definitely choose hospital care. Of the 46 families whose child died at home, there is one mother who said that although she cared for her child at home, she would definitely choose the hospital if she had to do it again. Of the mothers and fathers whose child died in the hospital after having home care services: six said they would definitely choose home care; one might, four were not sure, one might choose the hospital, and four parents representing two families, would choose the hospital again. The same pattern was seen in the ratings by parents of satisfaction with home care services: 97% were very satisfied with the nursing services provided and 3% were somewhat satisfied. Of the mothers and fathers of the children who died in the hospital, 11 (79%) were satisfied and three (21%) were not satisfied. The three parents who were not satisfied represent two families who would definitely choose hospital care if they had to choose again. It is of interest to note that the two nurses who worked with these two families state that they would not be willing to provide home care services in the future. Examining these instances more closely, there were several areas with these families in which severe communication problems existed between the parents, nurses, coordinators, and physicians.

Table XIV

Visits to Clinic by Children During Home Care in Phase One

No. Visits	Children Who Died at Home		Children Who Died in the Hospital	
	Number	Percent	Number	Percent
0	30	65.2	4	33.3
1	8	17.4	4	33.3
2	1	2.2	1	8.3
3	0	-	1	8.3
4	1	2.2	1	8.3
5	4	8.7	0	-
9	0	-	0	-
10	0	-	0	-
14	1	2.2	0	-
15	0	-	1	8.3
19	1	2.2	0	-
Total	46	100.1	12	99.8

Conclusions

The institutions who assumed the care delivery aspects during the third and fourth year of the grant are the University of Minnesota Hospital Home Health Services Department, Minneapolis Children's Health Center, and St. Louis Park Medical Center, along with the public health nursing agencies throughout the state. The institutionalization of this model of health care delivery for the dying child has now been expanded to include children dying from causes other than cancer at both the University of Minnesota and Minneapolis Children's Health Center.

Findings of this study suggest current practices might be changed with the nurse assuming more responsible and accountable roles than is now the usual practice, with close collaboration with physicians. This study challenges the requirement for a medical director for hospice programs, as well as the requirement for a multi-disciplinary team including volunteers. Direct reimbursement for nursing services would be essential for the cost-effectiveness

to be passed on to the public. Further research needs to be done to determine the benefits and limitations of nurse-directed health care systems.

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Communication

The Cost of Home Care for Dying Children

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A comparison of costs for comfort care for the final days of life of children dying of cancer at home or in a hospital is made. Depending on the comparison groups used, the costs for hospital care are about 22 per cent to 207 per cent more than for home care. Variation in comparisons depends on whether the home care is purely an alternative to inpatient hospitalization or representative of a larger concept of care that includes added services at times when the child would not necessarily be hospitalized.

A RESEARCH PROJECT entitled "Home Care for the Child with Cancer" was initiated by the University of Minnesota School of Nursing in 1976. The purpose of the study was to assess the feasibility and desirability of family-centered home care for children dying of cancer. One aspect of the feasibility and desirability of such a program is cost.

Community-based home care services have been available in the United States since the early 1900s[1] and hospital-based home care programs have been in existence since 1947, when Montefiore Hospital began its home care program in Bronx, New York.[2] The model of care developed by this project followed these traditional home care services closely, although hospice concepts such as comfort care were widely used.

Studies of community- and hospital-based home care programs for adults have shown that home care services are usually less expensive than institutional care, sometimes half as expensive or less expensive when compared with hospitals or nursing homes.[3–6] However, traditionally, third-party payors and governmental payment sources, (e.g., Medicare and Medicaid) have had restrictive policies concerning home care services.[7,8] A major issue seems to be that third-party payors have continued to be concerned that home care will not be used as a substitute for institutional care, but rather as "add-on" health care services that will increase rather than decrease health care costs. The present report explores the cost of comfort care at home for children dying of cancer as both a substitute for inhospital care and an add-on service.

The Home Care study was divided into two phases. During the first phase, which is considered here, a model of home care services was developed and evaluated.

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That model provided comfort care for children in the end stage of cancer, i.e., children who were expected to die in the near future. Parents were the primary caregivers, nurses coordinated the care, and physicians consulted with the family and nurse. Administration of the home care services was separate from existing nursing services. Home care nurses were hired on an hourly basis and were recruited from health care institutions and agencies in the family's community. Project staff nurses oriented the newly recruited home care nurses to the special functions they would serve and provided consultation throughout the home care period. The home care nurses were on call to the families 24 hours a day, 7 days a week. They assisted the families by providing a broad range of services, including teaching, health assessment, physical care, and emotional counseling, as well as the procurement of medical equipment, supplies and medications. The nurses made home visits whenever the families requested and maintained frequent telephone contact with the families. During this first phase, research funds paid for all home care costs.

From July, 1976, through June, 1978, 58 families with terminally ill children participated in the study. During that time, 46 (79 per cent) children died at home, 11 (18 per cent) returned to and died in the hospital, and 1 (3 per cent) died en route back to the hospital. General descriptions of this research are reported elsewhere.[9–11]

Inclusion in this home care group of 58 families was based on physician referral and the following criteria: 1) The child was younger than 18 years of age; 2) Cancer cure-oriented treatment was stopped and new cure-oriented treatment was not planned; and 3) The child was expected to die in the near future (within days or several weeks). Although all the children who were accepted fit these criteria, the health status of some children improved. For instance, some children outlived their terminal prognosis by 3 or more months, and some children improved sufficiently to return to school. In 12 instances, the children were so stable that although a decision to stop cure-oriented treatment had been made before entry in the study, the parents and physician decided upon additional chemotherapy. Those children later stopped chemotherapy before death. These "improved" children were not removed from the study. Instead, they continued to receive home care services during their periods of improved health as well as when their health failed later.

Methods

To determine the cost of this home care delivery service as a substitute to in-hospital care and an "add-on" service, several comparison groups were developed. It was necessary, first, to determine the portion of care that could be characterized as "final care." Therefore, to provide a basis for cost comparisons, operational definitions of "final care" in both home and hospital care were developed. For home care, the entire length of time following referral and acceptance into the program was regarded as final care. For hospital care, final care was regarded as starting when the child was receiving only comfort care. Comfort care included pain medications and intravenous feedings. A child who died in the hospital while being actively treated for cancer would not fit the definition.

To develop a comparison group of children who received final care in the hospital, a search was made of University of Minnesota Hospital records for the years 1976–1978. The search revealed 12 children who had died of cancer at University Hospital and who had received only comfort care for the last part of their final hospitalization.

In theory these 12 children would have been eligible for home care. Why they did

not participate in home care is unknown, but there could be numerous reasons, e.g., it was not offered to them because of individual differences in physician attitudes toward the (then) new home care alternative; home care may have been offered, but the parents turned it down; it was more convenient (although not necessarily better) to let the child remain in the hospital. Examination of the medical records of these 12 children revealed no obvious differences in diagnosis or treatment, compared with the 58 children in the home care group, other than length of time between end of cancer cure-oriented treatment and death. Itemized hospital bills were available for 11 of the 12 children—these 11 children, therefore, constitute the hospital care comparison group reported below (Table 1, Group A).

Three home care comparison groups were developed. Group B, Table 1 was composed of the 46 children who died at home while receiving home care services. From Group B, a subgroup of 20 children who entered home care directly from inpatient hospital care was developed (Table 1, Group C). This subgroup was selected because children in this home care group and the hospital care group described above were hospital inpatients at the time final care began. The length of home care for the total group of 46 children who died at home was a mean of 39.1 days. For the subgroup of 20 home care children who were inpatients before entry to home care, the mean length was slightly shorter, i.e., 33.0 days.

The hospital group children had received final care for a mean length of 8.0 days. To match the children more closely on length of care, a second-comparison subgroup (Table 1, Group D), a subset of those 20 children, was composed of 11 children who were matched with the 11 hospi-

TABLE 1. Components of Average Daily Cost* of Home and Hospital Care

Cost Item	Received Final Care in Hospital	Received Final Care at Home		
	Group A (n = 11)	Group B (n = 46)	Group C (n = 20)	Group D (n = 11)
Room and board	$158.09	NA	NA	NA
Nursing care		$40.04	$ 52.44	$ 65.90
Room Furnishings	27.69	2.59	2.37	5.06
Equipment		3.49	4.54	7.26
Supplies		2.99	4.40	6.23
Medications	12.94	2.54	2.65	4.10
Laboratory tests	81.19	0.14	0.10	0.17
Home care program coordinator	NA	14.46	15.28	29.40
Clinic visits	NA	0.67	0.51	0.54
Hospitalizations	NA	1.48	3.40	0
Physician hospital	14.00	NA	NA	NA
Physician home	NA	1.72	1.41	0
Other personnel	0	0.21	0.05	0.08
Other costs	12.01	7.17	16.48	29.96
Totals	$305.93	$77.50	$103.63	$148.60

Group A, Hospital care—died in hospital; Group B, Home care—died at home; Group C, Subset of Group B who were inpatients before home care; Group D, Subset of Group C based on matching with Group A.

* Cost shown for each category is the mean daily cost per patient averaged across all patients within each comparison group.

tal care children on the basis of the length of final care received. Each of the 11 children received final care at home for a period of time that matched within 2 days the length of final care received by the 11 children who received their final care in the hospital. The mean length of final care then was 8.0 and 8.3 days for Group A and Group D, respectively.

Results

Table 1 shows the cost of various categories of items for each of the comparison groups. Most of these costs (e.g., costs for medications) varied daily for each patient. The mean cost for each category, therefore, was first calculated for each patient. Then, to provide some combined figure for the cost of each category within each comparison group, the mean costs for each patient were summed across all patients within each group and divided by the number of patients within that group. The use of this average of the average cost per item reduces the effect of unusually high or low costs found in some instances.

Dollar amounts used in Table 1 represent 1977-78 cost rates calculated as follows. Amounts used for the 11 patients who received final care in the hospital came from the patient's actual hospital bill for all items except physician fees, which are billed separately. Physician hospital fees were calculated at $15.00 per patient per day. For the home care groups the figures shown are estimates based on the cost of such goods and services at rates charged by local agencies. For actual home care programs, various community agencies, notably the American Cancer Society, will supply some items without charge, e.g., a hospital bed in the home. The figures in Table 1 represent real costs if each item had to be paid for.

As shown in Table 1, no cost is included for room and board at home, since that is a normal part of a child's daily expenses. Nursing care costs for the home care cases are for nurse home visits, including the nurses' travel time and expenses, and the nurses' agencies' (e.g., public health agency) overhead expenses (but not the home care coordinator expenses, which are listed separately). The home care nurse visit rate used was $35.00 for the first hour of a visit and $10.00 for each additional hour. This is the rate used in the Minneapolis-St. Paul metropolitan area.

Costs in the categories of "room furnishings," "equipment," "supplies," and "medications" are for items such as hospital beds, over-the-bed tables, antipressure devices, suction machines, incontinence pads, dressings, and intravenous feedings. Reported costs are for items that were secured or dispensed, regardless of whether or not they were actually used or consumed.

Costs of laboratory tests are for the test itself without any special costs involved in drawing the test sample at home, e.g., sending a laboratory technician to the home; those other costs are included in "other personnel" costs as appropriate. In fact, laboratory tests were rare in the home care group, and when they did occur it was usually during clinic visits. Occasionally, children in home care would be seen in outpatient clinics or doctors's offices. In the cost calculations, the flat rate charged by the University of Minnesota clinics for such a visit was used. This rate includes a $10.00 charge for the clinic and $12.00 physician charge for each visit. Other items during clinic visits, e.g., laboratory tests, are included in their respective categories.

Home care program coordinator costs covering the nurse coordinator and overhead were figured at $10.00 per hour. Coordinator time was estimated at 1.5 hours spent on patient referral and intake (for family contact and location of a home care nurse), 1.5 hours per week during the time of home care (for home care nurse education and support), and 1 hour after the child's death (to close the case). Contacts by either home or hospital staff with the family after the death of the child were

not included in the cost figures for either home or hospital care because these costs are usually not reimbursable.

Three of the 46 children who died at home were hospitalized briefly and then discharged during the period of home care. For consistency of comparison, the cost for their brief hospitalizations (including all items involved) was calculated at the same general rate that was used for the hospital care group, i.e., $305.93 per day. Because these hospitalizations were brief and because the return to home care was anticipated in all cases, home care arrangements were left in place during the hospitalization. In a sense, these children had overlapping care for a brief period, which the costs in Table 1 reflect.

Physician visits to the home during home care were infrequent. Because there were no data available on the charges made for these visits, it was necessary to use estimated costs. Considerable discussion with various physicians and third-party reimbursers suggested that a cost of $75.00 per visit was a reasonable estimate. Many will find this estimate excessively high or low. This debate, however, is of minor importance in this study because the cost of physician home visits is such a small component of the overall cost of home care in this model, as can be seen when converted to the average of each patient's average daily cost.

"Other personnel" costs for home care included the occasional home use of individuals, such as laboratory technicians, physical therapists, or home health aides. "Other costs" in the hospital included sundry miscellaneous items; for home care the "other costs" chiefly were ambulance transportation.

It can be seen in Table 1 that the daily cost of home care is about half that of the daily cost of hospital care, when comparing the hospital group (A) with the home care group (D) most closely matched on length of final care. The largest differences appeared in the costs for equipment, supplies, medications, and laboratory tests. Equipment and supplies were twice and medications over three times as costly for those in the hospital group. Laboratory tests represented 27 per cent of the daily cost of final care in the hospital, whereas those charges were negligible in home care. For longer duration of home care, i.e., the other two home care groups (B & C), the *daily* cost of home care relative to hospital care is even less. As stated previously, the health status of the children in Groups B and C was different from Group D. This ranged from some children in Group B, who, although diagnosed terminal, had time to attend school, to Group D children who were severely ill and died in an average of 8 days. Therefore, the children in Group B who were not as severely ill throughout their home care experience had the lowest daily home care cost and the Group D children who were severely ill had the higher costs. Group D children still had lower costs than the hospitalized children.

Table 2 presents cost data in a slightly different manner. Cost estimates used in Table 2 were the same as those used in Table 1, however, in Table 2, the actual total cost per patient (not an average average) was used in calculating the figures shown. Table 2 shows that even though the home care group of 46 children (Group B) had a mean of 39.1 days of final home care, the mean total cost of their care was $1,414. This was still less than the $1,726 mean cost for the children in Group A, whose final care lasted only 8 days. Thus, depending on the comparison group used, hospital care was about 22 per cent to 207 per cent more costly than home care.

If we had been less restrictive in our definition of when comfort care only began in the hospital, the cost of hospitalization would have been greater. In a preliminary cost comparison reported elsewhere,[9] the mean length of final hospitalization of 22 children who died of cancer in the hospital

(including those receiving various degrees of cancer treatment) was 29.4 days, with a mean total hospital cost of $13,022.

Discussion

One important issue that must be addressed in examining certain costs of the comparative costs listed in Table 1 is: were the differences because of the presence of different populations (i.e., the children in the groups are not strictly comparable) or, alternatively, were there differences in application policies? That is, what accounted for the increased costs for equipment, supplies, medications, and laboratory tests in the hospital group? While we cannot rule out differences between the groups based on medical need, care was taken to match these groups as closely as possible. Therefore, we believe that the observed cost differences result from differences in approach to terminal care, not need for care.

The focus of the home care was to make dying children as comfortable as possible in the last days of their lives; not to avail them of all of the sophisticated services that only a hospital can offer. Medications used at home focused on pain control and other comfort measures, not disease control (e.g., antibiotics were rarely used at home). The laboratory test difference is significant and not surprising. The utility of diagnostic laboratory tests for children in their final phase of life should, in our opinion, be seriously questioned. The results of these tests usually have no bearing on the child's comfort care, and appear to be routinely ordered, especially in teaching hospitals. Few question why a dying child's physical demise is closely monitored, where no action would be called for, whatever the results might be.

Anecdotally we can report a case where a physician ordered an end to laboratory tests for a dying child in the hospital, only to find that his replacement later in the day (exercising his own judgment) ordered further tests. In another case a parent questioned the rationale for drawing a blood sample when it was apparent that the child would be dead before the results came back.

That we believe such laboratory tests are an unnecessary cost for such children is one issue. That they are also uncomfortable for the child is of further concern. This attitude toward minimal use of laboratory tests for terminal patients is shared by hospice programs in England and generally those in the United States and Canada.[12]

The data presented indicate that our home care model for comfort care in the final days of life of a child dying of cancer is clearly less expensive than hospital care. When viewed strictly as an alternative to hospitalization, home care was, not surprisingly, much less expensive.

TABLE 2. Comparison of Estimated Total Cost of Final Care

	Received Final Care in Hospital	Received Final Care at Home		
	Group A (n = 11)	Group B (n = 46)	Group C (n = 20)	Group D (n = 11)
Mean duration of final care (days)	8.0	39.1	33.0	8.3
Mean total cost	$1,726	$1,414	$1,128	$561

Group A, Hospital care—died in hospital; Group B, Home care—died at home; Group C, Subset of Group B who were inpatients prior to home care; Group D, Subset of Group C based on matching with Group A.

From the comparison groups presented, it is clear that the home care services received were not only direct alternatives to hospitalization. That is, many of the children were not hospitalized at the time of entry and probably would not have spent a comparable number of days in the hospital had there been no home care available. Thus, the costs associated with home care for many included additional, or "add-on," services that were not alternatives to expensive hospitalization. Still, when viewed as a package cost, the total cost of home care for a mean of 39.1 days was still less than the total cost of hospital care for a mean of 8 days.

This is also how we prefer to view the model. Home care does not necessarily begin when the child would otherwise by hospitalized. Rather, home care starts when the decision to cease active cancer treatment, coupled with the probability of death in the near future, is made. That is the time when the care should begin, even if it is an addition to our present health care services.

The 12 children who were in home care but then died in the hospital (or en route to it) were not considered in the cost figures. It is not possible to determine how many of their days at home were purely alternatives to hospitalization and how many were not. However, of those 12 children, six children spent 1 day or less in the hospital; thus it would appear that, overall, some cost savings resulting from home care occurred even in the cases where the child did not die at home.

We would conclude that home care for dying children is feasible and desirable from a cost standpoint, although it requires some rethinking of current cost reimbursement guidelines. To realize moderate to substantial savings, third-party payors who normally cover hospitalization need to be willing to pay for what they view as additional services, to save themselves the cost of hospitalization later.

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Professionally Speaking

D. Gay Moldow

Ida M. Martinson

From Research to Reality—Home Care for the Dying Child

A pilot program that provided home nursing care to the dying child with cancer helped local health care institutions develop their own home care programs

In 1972 Ida Martinson provided nursing care for a young patient who was dying of leukemia. The child's family had decided to try to keep their son at home until his death because he strongly wanted to be with his family. Dr. Martinson supported and counseled the parents, while they assumed care-giving responsibilities and provided comfort to their child through the final stages of his illness and death.

This experience encouraged Dr. Martinson to continue providing home nursing care for children dying of cancer. During the period of 1972 to 1976 seven more families participated in a pilot project that provided care at home for children dying of cancer. Home care services were provided by nurses who volunteered their time, and monetary gifts from the families helped defray transportation costs.

On the basis of data gathered during the pilot project, a research grant was written in 1975 to study the advantages of a child remaining at home as an alternative to hospitalization for the child dying of cancer. The research grant proposal included two phases: the first consisted of two years of direct home care services to dying children. During this time information would be obtained before and after the patient's death from those family members and health professionals involved. These individuals would also be interviewed to assess home care services. During the second phase the grant staff would work to help local health care institutions (hospitals, clinics, and public health agencies) develop permanent home care programs for children dying of cancer. These would be located in the community and supported by local personnel. This phase would be evaluated to determine whether the community programs were in place and functioning.

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Phase I—Direct Service

In 1976 the direct service phase of the Home Care for the Child with Cancer project began.* The primary subjects in the program were members of 63 families; in each a child, 17 years of age or younger, had cancer and was dying from it. The actual admission criteria to the program was the physician's assessment that the child probably would not live much longer, and that he planned no further hospitalization for treatment.

METHODS. Home care services were administered from the research project office, and were separate from existing community nursing services. The research project staff nurses were responsible for locating and hiring nurses in the community who would serve as home care nurses. These included nurses from local public health agencies, hospitals, and clinics; nurses who were neighbors or friends of the family; and other nurses in the family's community. The primary function of the project staff nurses was to orient home care nurses with the special role they would play in caring for the dying child. The project nurses also consulted with the home care nurses and in some instances provided a limited amount of direct home care services. In general this procedure was followed:

- The child was referred to the project.
- After this, the family met with a project nurse to discuss the program.
- Once the child and his family agreed to participate, a primary home care nurse was hired from within their own community. At this time a back-up nurse was also assigned to provide services whenever the primary nurse was not available.
- Next, whenever possible, the primary nurse met with the family in the hospital before the child was discharged.
- The nurse and the parents discussed care for the child and talked about what to expect as his condition progressed and deteriorated including the changes preceding death.
- Finally, they spoke about what to do when death occurred.

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As principal care-givers, parents were encouraged to take over as much of their child's care as they wanted. The nurse was always available to provide teaching, direct physical care, and emotional support. In addition she assessed the need for equipment and supplies and arranged for securing them. She was on call 24 hours a day, seven days a week, ready to go to the family's home whenever and as often as they asked for her.

During the period of care, a referring physician was available to the nurse and the family, with the nurse performing the important role of intermediary between the family and the physician in obtaining medications and advice. In some instances the family kept in close contact with the physician, but in others the nurse was the primary health care contact and used the physician as consultant. Some physicians examined their patients in outpatient clinics and some, rarely, at home.

When the child died, the nurse helped family members with physical care and provided emotional support. She facilitated the removal of the child's body and arranged for a death certificate. Afterward she attended the child's funeral and visited or telephoned the family for several weeks, sometimes for several months, after the death.

Research data was accumulated from interviews with the parents, the nurse, the physician, and siblings, grandparents, or clergy when appropriate. The child's medical history was abstracted, and all services provided the child—including home visits, telephone calls, hospital visits, and other interactions—were documented.

RESULTS. During the first two years, 63 children were included in the study. At the end of those two years, three boys and two girls were still living. Of the 58 children who died, 46 died at home. 11 re-entered and died in the hospital, and one child died in an ambulance enroute to the hospital.[1-4]

Therefore, results indicate that home care for children with terminal cancer which enables these children to die at home is clearly feasible. There are no insurmountable obstacles involved. However, to work effectively, home care requires some role changes: parents become the primary care-givers rather than nurses and physicians; physicians must be more flexible in their prescription of medications; and nurses assume more responsibility for the direction and co-ordination of home cancer services.

Highly important to the success of a family's endeavor to keep their child at home until he dies is a change in the attitudes of all involved. Parents and health officials have to accept that the child is dying and understand when his condition changes for the worse it does not mean the child should be rushed to the hospital.

Parents and health personnel have to accept that when a child is dying, it does not mean rushing to the hospital.

Phase Two: Groundwork

Preliminary groundwork for the incorporation of research nursing activities into existing community health services was laid at the beginning of the project when two advisory committees were established. They were: (1) a community advisory committee consisting of nursing representatives from local public health nursing agencies, nurse clinical directors, and directors of nursing from local hospitals and the Minnesota State Department of Health, and (2) a committee of nurse clinicians who worked with children with cancer at the hospital with which we are affiliated. These advisory groups met regularly with the project staff for the purpose of assessing and evaluating the results of the study. They also consulted with the staff; made referrals; and provided other invaluable services, including: taking information about the research project back to their institutions and teaching the staffs of those institutions about the project. All the while they strongly supported the principles and aims of our project.

Another important preparation step was educating the medical and lay community about home care for dying children. For this we presented lectures and conducted workshops throughout Minnesota, expanding to adjoining states and then nationally. We were active on committees in the health community. For example, one of the project staff served on the American Cancer Society's educational committee on childhood cancer, another on a hospital home health services advisory committee, and others on volunteer committees concerned with the care of families confronting death through terminal illness. We prepared written materials and made them available to the medical community. Along with general information about the research project and the results of the project, these materials offered specific nursing care information—knowledge we had gained while providing this highly specialized home care during the research phase of project.

Since the pilot phase, parent consumers had been consulting with us on the research project. Some of them were members of Candlelighters, which is a nationally organized group of parents of children who have cancer or have died from cancer.* Their assessment of the current services and research results were frequently asked for and used. These parents often discussed home care with other parent members, and the project staff arranged for volunteers to act as consultants during the direct service phase to help us assess consumer interest in establishing permanent home care services.

Approximately half way through the project, our staff began planning to incorporate the program of home care for dying children into the three health care agencies that had referred the most children to us. We met with representatives from these three facilities and explained that

*For more information on Candlelighters, write: 123 (C) Street SE, Washington, D.C. 20003

the funding for direct service would end soon, but we wanted to encourage and support the development of permanent home care services for dying children within local health care agencies. We asked for an opportunity to show the results of the research project to their agency staff members, administrative officials, and boards of directors. Meetings were arranged for us with the three agencies, and similar meetings were set up with smaller community agencies.

Three Actual Programs

By the end of the two years designated for the service phase, the three local agencies had established or were in the process of establishing permanent home care programs that would aid families whose children were dying. The institutions included (1) a 700-bed university hospital that serves as a cancer referral center for six states, (2) a 100-bed private pediatric hospital that serves primarily local residents, and (3) a large private clinic that services both local and referred clients.

Each program begun by the three institutions followed the policy guidelines for the provision of home care services for dying children that we developed and used in the research project. Furthermore, the home care program co-ordinators at the two hospitals expanded home services beyond the original criteria. This means that children are admitted to the home care programs in these two hospitals before the acute dying phase, at the point in their disease when the hospital staff feels the family needs extra help at home to cope with physical and/or emotional problems. For instance, a two-year-old child who was receiving outpatient cancer treatment needed additional nutrition. The home care nurse showed the family how to administer the nutritional supplement at night using a Broviac® catheter. Each of the three home care co-ordinators at these institutions were given the responsibility of locating and hiring nurses to work with the families involved. The three specific programs developed were:

UNIVERSITY HOSPITAL This large institution already offered home health services but primarily to adults. Although the department was small it was well supported by the hospital. An additional nurse was assigned to the home health services staff, with the intention that she would focus on home care for dying children. This resulted in a staff team that included a pediatric staff nurse, an adult staff nurse, and a co-ordinator—with the pediatric staff nurse and the co-ordinator providing direct care services to dying children.

PRIVATE HOSPITAL The small private hospital did not have a home care department before their involvement with the research project. But they were very committed to family-oriented care and community service, and anxious to establish a home care program. Approximately six months before the service phase was to end, the hospital board and administration organized a home care planning committee to be co-ordinated by the director of nursing, which included nurses who had participated in the home care project, representatives from the departments of nursing, psychology, and social work, and parent volunteers. They drafted policy statements and located the administration of the home care program in the department of nursing. A home care nursing co-ordinator was hired and given responsibility for developing the program. She was also responsible for discharge planning and patient education.

PRIVATE CLINIC This is a large, private clinic which serves local clients. Throughout the research project the pediatric-oncology physicians in the clinic were supportive of the concept of children dying at home and referred all of their appropriate patients to the project. The services that the clinic provided prior to the research project included consistent nurse and physician clinic coverage and 24-hour telephone availability of the physician and nurse, from the time of diagnosis or referral to the clinic, until death. The clinic administration decided that the nurse who had been providing this co-ordinated care to the clinic families would expand her responsibilities to include co-ordination of a home care program for dying children.

Throughout the second phase the research project staff provided support to the new program co-ordinators. A project staff member was available on a 24-hour basis and frequent telephone contact offered information, answered technical questions, and helped anticipate potential problems. Program co-ordinators and the project consultant met monthly for educational and support purposes; medical equipment was loaned to the new programs; and minimal financial support was given. Along with this, all project written materials were made available to the program co-ordinators and newly obtained research results and knowledge shared.

While working with these three agencies, the project research staff continued to maintain contact with and encourage the development of home care in community public health nursing agencies. Most of these agencies did not provide home care for dying children before the research project was activated, and had to make policy changes along the project's guidelines—for instance provision of 24-hour coverage.

A major concern about integrating research findings into practice is whether insurance companies will pay for them.

Results

At the end of the second year of operation of the direct service phase five children who initially had been referred to the project were still alive. Two children were close to death, but the other three were stable. One child who was very ill was referred to the local institution his

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family's physician was affiliated with, since that institution had by that time established a home care program. A second child had been receiving home care services from a public health nurse with co-ordination from the project staff, and these public health nursing services were continued. The families of the other three children who were stable were given information on the home care programs recently established within their communities, so they could obtain necessary assistance in the future.

During the phase when programs were being developed in local health care agencies—the third year of the grant—17 children were cared for by the home care programs at these three local institutions. All the children were 17 years of age or younger. We could not evaluate the results of one case because the family did not comply with interview procedure after the death of the child. At the end of the first year, nine boys and four girls had died; of these 13 children, ten died at home and three died in the hospital. The child who was cared for by the public health nurse died at home. The large, referral hospital program cared for 13 children; of these five died at home and three died in the hospital; five are still living. The small, private hospital program cared for two children: one died at home and the other is still living. The private clinic cared for four children, three died at home and one is still living.

Funding

One of the major concerns about incorporating research activities into local health care services has been whether private insurance companies and government funding sources would pay for these specialized home care services. All of the nurses who provided home care as part of one of the three programs were paid. They were paid in a variety of ways. Five of the nurses were paid by their public health agency; the agencies utilized community funds to absorb the cost. Four of the nurses were paid by the family's insurance company. The insurance policies used have covered 80 percent of the costs and the family or the institution providing the home care covered the remaining 20 percent. County funds in the form of medical assistance paid for two. One nurse was paid by the research grant and another was given a gift by the family.

The Factors of Success

This research design has led to successful incorporation of home care services in three institutions in our community, as well as acceptance of home care for dying children in communities outside our local area. We feel the important factors that contributed to the program's success were:

(1) The incorporation phase was part of the research design. Therefore funding was included for activities to develop programs in local health care agencies.

(2) Health professionals in the community were involved with the project from the beginning. These professionals were kept up-to-date on the development of the project and served as consultants throughout the project.

(3) Lectures, workshops, meetings and personal communication between the project staff and health professionals in local, state, and national agencies helped teach the health community about home care delivery and the progress of this project. A hospital, physician, or nurse can no longer say "that can't be done" because these health-providers have learned that home care for dying children is feasible.

(4) This project used lay consumers. Parents of the children who were dying became involved in the project during both the service and institutionalization phases, as parent consultants and as advocates for home care in the community. In a personal way and as members of Candlelighters, these parents supported the project and spoke out for the concept of children dying at home. Also, as consumers they requested the services offered by the project and insisted these be made available to them.

(5) Our Home Care for the Child with Cancer project began in the right place at the right time. When our program began the community was showing increasing interest in the problems of death and dying, with consumers making more demands on their health care system. For instance, Minnesota was the first state to make a law that the Patient's Bill of Rights must be posted in every hospital.

Moreover the project's intensive educational efforts served to persuade those who were skeptical or opposed to the program that children could be cared for at home until they died. At the point when the direct services offered by the research project ended and it was suggested that the community now provide such services, health care agencies had already accepted the concept as their own and assumed they would begin to provide the service.

We have two final suggestions in the area of education that will help the future transfer of functions from research projects to health care institutions. The first is the provision of more direct education during the service phase, for example, between the primary nurses, the community agencies, and project staff. In our project much of the primary nurse's education was provided over the telephone—this occurred because of distance problems. However, more face-to-face communication would have contributed to making community professionals more knowledgeable and probably lead to an earlier and greater acceptance of home care. The second area where further education about children dying at home should be provided is in schools of nursing. Surely this and similar programs will benefit greatly from the knowledgeable support of the young women and men who are entering our profession of nursing.

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The CHAIRMAN. With that, we will recess this hearing until further notice and we will see what we can do in this particular Congress to resolve these difficulties.

[Whereupon, at 12:34 p.m., the committee was adjourned.]

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